

**Exploring the meaning of participation in nursing  
care: the old persons' perspective in the community**

**Ekaterini Kasidi**

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## DECLARATION

I declare that this thesis has been composed by me and it has not been submitted for any other degree or professional qualification except as specified.





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## **ABSTRACT**

It is evident in the literature that there is no clear definition of the term participation. Researchers that deal with this issue mention that it is a term that is used with the same meaning as patient collaboration, patient involvement, patient partnership (Ashworth et al, 1992; Cahill, 1998) and even self help. This study aims to uncover the meaning of participation in nursing care for old persons living in the community.

The Husserlian phenomenological approach was chosen to investigate the phenomenon. Twenty three old persons living in the community were recruited through four open day care centres in both urban and rural Greece. Unstructured interviews were performed in order to obtain their views and experiences regarding the issue under investigation. Collaizzi's method of data analysis was employed to analyse the data.

Furthermore, phenomenological research is suggested to be an efficient way of getting to know other people's reality in order to plan future care and use the information to improve the existing services. That is because the clients' needs can be identified, therefore, the results of a phenomenological research can contribute in the provision and justification of high quality care.

This thesis calls for a change of attitude of nurses so that people are prepared to participate as they wish. There is a change of culture in the provision of health care as information is now accessible from many sources and people feel more responsible regarding their health and managing their illness. In addition, the context of community, where old people are at home, makes them feel more in control and able to participate in all aspects of nursing care.

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# **CHAPTER 1**

## **An introduction to the study**

### **1.1 Introduction**

This chapter constitutes an overview of the thesis. Firstly, I will state what initiated my involvement in this research project. Furthermore, I will define my research question and its aims and justify why this study is worthwhile. The next issue that needs to be given a brief description is the Greek context as the research will be conducted in Greece and some clarification is needed for future reference. In addition, after careful thought and consideration of the literature I made the decision to write in the first person, claiming a strong authorial identity. I will explain and support my decision to the reader. Another issue that I felt it was of the utmost importance to be clarified is the use of specific terms to address those involved in the research project in order to prevent potential confusion to the readers. I will finish with the outline of the thesis.

### **1.2 Background of the study**

Some years ago, during my nursing studies I chose to do my practical training in gerontological nursing. Part of my training was community care of old persons. I became actively involved in the provision of nursing care for old persons that lived at their own homes. It involved mainly going to their homes and providing nursing care such as post-operative care, injecting medication, blood pressure measurement,

mobilising after serious accidents. Occasionally it involved palliative care for cancer patients. These interventions involved teaching them certain techniques and educating them in cases that needed long term care so that they could maintain a satisfactory level of independence. In such cases I observed that each person had a different approach and they wanted to participate on their own terms. There were several occasions that they associated their involvement in their care with their ability to remain independent.

It was the type of nursing care that I saw as having much unexplored potential, in the context that was practised then. I had the feeling that more could be done and the full benefits were not yet explored. I was particularly interested in this area of nursing because it gave old persons in need of care the opportunity to remain active members of the community, as opposed to becoming institutionalised.

The issue of old persons' participation in nursing care became interesting for me and I started looking closer at my interactions with them. What became clear to me was that nurses did not have the same viewpoint with them, and there was a wide variation of viewpoints among themselves as well. My interaction with the old persons gave me the opportunity to gain an insight of the wealth of the old persons' experiences as well as their need to be heard.

### **1.3 Research question, aims and justification of the study**

Drucker's paper (2001) in 'The Economist' explained what changes are expected in future society and how we can be prepared for them. He predicted that by 2030 the age of full retirement will be mid 70s in all developed countries, which means a major change in the social and health care setting. According to him Greece, Italy and Spain are the first countries to face this major change which will probably occur before 2030. Therefore, in Greece, social and health care changes, due to the increasing number of old persons, are already a significant election issue and a social problem of great proportions.



According to the latest census in Greece in 2001 (National Statistics of Greece, 2002) in a total population of 10,964,020 people, 2,030,585 are aged sixty five and above. The percentage of older persons has doubled in the last ten years while the population of Greece has remained the same. Moreover, people under the age of fourteen are 1,548,208 while the previous census counted 1,974,867 of them (National Statistics of Greece, 2002), which is alarming news. As reported by the Greek Ministry of Health and Welfare (2003) there is a significant change in the age distribution of the Greek population in comparison to the earlier census in 1981 (persons over 65 increased by 791,044, persons 0-14 years old decreased by 758,000 persons). In comparison to the rest of Europe it is reported that Greece has the highest percentage of people aged 65 and over (Ministry of Health and Welfare, 2003).

At the same time the demands for free social and health care have increased over the last ten years and as a result the money that is spent in order to cover these needs have doubled (Eurostat, 2002). Although demand for more money is rising due to the increasing number of the ageing population (pensioners), the decreasing number of births as well as the high rate of unemployment reduce the funds for health care (Eurostat, 2002). Therefore, it is important to improve the existing services without increasing the cost.

The concept of patient participation has been included in the declaration of Alma-Ata of the World Health Organisation (1978) and since then it has triggered a significant change in the national health care systems all over the world. One by one, the members of the World Health Organisation embodied the concept in their directives as well as health care professionals in their practice as an answer to the above issues. In this particular situation when there is evidence that the role of the old persons is meant to change we should embrace new practices and develop services that cover the needs of our times. The literature shows that participation could be an answer to the complex issues that arise in the health care setting due to the increase of the population of old persons. The significance of this study lies also on the growing

importance of participation for the modern societies and the modern health care systems.

A search in the World Wide Web and the electronic databases (Medline, Cochrane, and CINAHL) provided me with a large number of references concerning the use of participation in order to plan more effective care, increase cost-effectiveness of health care and user-satisfaction. Participation was also cited as a way of obtaining feedback for the provided health services. The international literature gave an account of the potential benefits and the significance of participation (Brearley, 1990; Cahill, 1996; Cahill, 1998). In a few words, participation and research about it is considered worthwhile as research provides evidence of numerous benefits, while it has just a few drawbacks and historically participation is gaining increasing acceptance and use by the public worldwide.

Brearley (1990) in her literature review suggested that patient participation can result in better management of resources and contribute to a better utilisation of the already existing health care services. Griffiths (1988) earlier, in his report on community care referred to it as more cost-effective than institutional care and suggested that participation can reduce even more the cost of health care provision in community and can contribute to a better management of resources. Therefore, it is important to know how people experience participation and the issues that concern its implementation in care.

Brearley (1990) in her literature review also presented examples of health insurance companies in USA that attempted to introduce client self-help in order to reduce the number of claims. This idea could be more significant in the future due to the increasing population of old people and the decrease of resources (National Statistics of Greece, 2002). Madan (1987) suggested that community involvement enhances the cost effectiveness of the provided services and contributes to the development of services that are more effective. Also, Brownlea (1987) referred to realising the fact that health problems are affected by the environment and the life style of people therefore participation can contribute to their effective management.

Latter et al (1992) pointed out that the proportionate increase in chronic, incurable conditions as well as in the number of the ageing population necessitate encouraging the individuals and their families to participate in their care and manage their own illness. Moreover Coulter et al (1998) explained that patients nowadays are able to understand that knowledge about illness and health is not the exclusive property of health care professions; therefore they are more motivated to participate. Demographic trends also result in putting more emphasis on the ability to be self-reliant and to maintain health over the longer lifespan that most people can now expect (Latter et al, 1992).

Literature has shown that participation could contribute to the planning of more effective health care services, and also increase the cost effectiveness of the already existing services. It can also contribute to the improvement of patient satisfaction. Providing though ethical care means that health care professionals have to understand a person's experiences (Shotton, 2003) and if participation is to be included in nursing care we need to understand what it means to them.

The meaning of participation is a fascinating issue as there are still researchers interested in defining it. Tutton (2005) has conducted action research on a ward to explore what participation means to frail old persons and health care workers. What proves to be fascinating about the issue of participation is that it has such a broad and diverse meaning in the health care context that researchers feel the need to determine what it means to different groups of people.

The question is what is the meaning of participation in nursing care for old persons living in the community (in Greece), by researching their views and experiences. The aim of the study is to gain an understanding of the meaning of participation in nursing care for old persons. Thus, my aim would be to let their voices be heard and their experiences presented and this may contribute to improving nursing practice, influence policy planning in the health care sector within the person centred philosophy and initiate more research in this field in Greece.

A literature search (see p 21-86) had shown that there is research conducted that explored many aspects of the issue but they were not focused in the actual experiences and views of old persons that I so valued during my field training in this field of nursing. I had the feeling that their voices needed to be heard with research that would be focused on these. A literature review in Medline, Cochrane and CINAHL did not identify any research about participation in Greece. It identified though, a research article by Gonos et al (2002) which gave an account of the research on the ageing population in the country and it was evident that recent research did not include the issue of participation at all. Therefore, exploring the issues concerning participation for those involved in Greece is needed. The lack of other research projects concerning the issue stresses the significance of the study.

In addition, on a personal level, for me this period of study (that initiated my involvement in this research study) was fulfilling due to my sensitivity towards old persons, as I was close to my grand-parents and the recent death then of my beloved grand-father. Growing up with grand parents and the close relationship I developed with them made me more sensitive for issues that concerned this age group. I lost my grand-parents quite young, after experiencing their sickness and suffering, as well as their complaints and difficulties with the NHS. Thus, I was motivated on a personal level to hear to other old persons' experiences and I could relate to them.

The question in any case was for me about how would I be able to communicate their own views and experiences and not my own as I could be personally involved due to my own experiences. As I mentioned above I could see that there were a variety of views and due to my experiences I had my own perceptions as other nurses had their own. What I then thought that would be of utmost importance would be to let their voices be heard and put my own views, as well as knowledge on the issue, as a nurse, and experiences on the side. If I wanted to offer them this opportunity I needed to find an appropriate research method.



## 1.4 The Greek context

Before starting to discuss the issue further it is important to provide some information about Greece as the study will be performed there. And we need though to acquire a better understanding of all issues concerning the participation for old persons in Greece. According to the Greek Ministry of Health (2003), Greece is a national state with roots reaching back at least five thousand years. The history of modern Greece began with the recognition of Greek Independence by the Ottoman Empire in 1832, which was the result of a series of revolutionary movements (Vakalopoulos & Vakalopoulos, 1985a).

It is located in the southeastern part of Europe, the first European Union member in the Balkans since 1981. Its population according to the latest census was recorded to be 10,964,020 (National Statistics of Greece, 2002). Greece has been a parliamentary democracy since 1975. It has a centralized administrative, political and economic system. Athens, the capital, is the decision-making centre of the country. However, lately implemented a decentralization program has been implemented, which still has to be tested by time to prove its effectiveness. Greece has managed to reduce its budget deficits and inflation which led to it joining the European Economic and Monetary Union in 2001 (Ministry of Health and Welfare, 2003).

Modern Greece underwent continuous radical changes as far the borders, the consistency of the population and the political establishment are concerned, from its establishment until 1975 (Vakalopoulos & Vakalopoulos, 1985b). The political unrest and financial implications of wars have influenced not only Greek culture but also the development of the Greek NHS. Although Greece has been a member of the European Community for over twenty years, its distinctive historical background makes its culture and NHS unique in comparison to its partners (Ballas & Tsoukas, 2004).

This research project is performed in Greece therefore a short description of the Greek National Health Care System (NHS) is needed so that the readers can

familiarise themselves with it for future reference. The Greek NHS provides a wide range of services that could potentially benefit the well-being of old persons in the community: day centres, day hospitals, long term nursing centres, centres of medical care for old persons, help at home and meals on wheels (Kyriakidou, 1995).

According to Theodorou et al (1995) historically the Greek NHS developed in four periods. The first period lasted from 1833 until 1922 and its main characteristic was the lack of resources. Therefore, there was no health care provision organized systematically by the state. Charity played a major role in hospital care.

The second period lasted from 1922 until 1945, a period characterized by the Great Recession and the impact of continuous war involvement. In 1922 there was a significant step as the Ministry of Health was established. In addition, the first legislation concerning social insurance and hospital management was implemented.

The third period lasted from 1945 until 1974. This period was a period of wars and political unrest. There was a lack of hospital beds and health care services and there was no investment or any systematic effort to organize the health care sector. In 1969, there was an attempt to implement the concept of family doctor and primary care but the dictatorship and political unrest prevented this from materialising. The fourth period lasts from 1974 to today. It is the period in which the National Health Care System was finally legislated and organized. Governments invested in building the infrastructure and educating and employing personnel to cover the needs of the population. The Greek NHS is a 'young' system in comparison to the rest of the European National Health care Systems (Theodorou et al, 1995).

According to the Ministry of Health and Welfare (2003) the Greek health care system is a combination of the Bismarck (health care is funded by social insurance) and the Beveridge model (health care is funded by the state budget). Greek residents can seek health care services in hospitals, health care centres of the National Health System services, in services belonging to Insurance funds, mainly to the Institute of Social Care Insurance fund (it is comprised of clinics and diagnostic centres), or in

private hospitals and clinics, diagnostic laboratories, private medical practises as reported by the Ministry of Health and Welfare (2003).

The Ministry of Health and Welfare (2003, p 40) pointed out that

‘the Private Health Care Sector has developed in tandem with the Public Sector’.

This statement suggested a problem. It is though officially attributed not to probable deficiencies of the National Health Care System (NHS) but to the large number of doctors who seek employment in the private sector as the NHS is not able to absorb a large number of them. Another interesting point is that the ministry admits that the growth of the private health care services can be viewed as a direct result of the fact that private services are financed by public insurance funds. As far as the care of old persons is concerned it is stated that it is provided mostly by the private sector, specifically the majority of nursing homes are private (Ministry of Health and Welfare, 2003).

As far as the administration of the Greek National Health Care System is concerned the Ministry of Health and Welfare determines the national health care policy and strategy (Ministry of Health and Welfare, 2003). According to the relevant announcement of the Ministry one of the objectives of the national policy for the elderly is to assure that old persons’ living conditions and support are appropriate so that it is possible for them to stay at their own homes and remain active members of the community (Ministry of Health and Welfare, 2003), however participation in health care is not included.

Kyriakidou et al (2001) argued that in Greece children feel that it is their filial duty to care for their parents. Nonetheless, the change in the family structure from the extended family to the nuclear family, the increase of divorces, the increase of families with none or one child and the unmarried couples are factors that influence the tradition of the family that will take care of the old. In addition, the longer lifespan that people are expected to have created a new reality of old persons that their children are willing to care for them but they are not able to do so as they are

also old and need assistance. In larger cities there is also the issue of space as modern flats are quite smaller and they do not allow extended families live together. There is though the tendency of parents living in the same neighbourhood with their children to enable daily contact.

Emke (1992) earlier had also pointed out the tradition of the younger generation taking care of their old. Also, the old usually have a network of friends that they can rely on. He mentioned that there are more aged women than men. In addition, he pointed out that there are significant differences in pension levels and there is a part of old persons that live in poverty or they are obliged to work although they have reached a pensionable age. This is more usual in rural areas with farmers.

The Ministry of Health and Welfare argued that institutional care for old persons has been tested in the past and proved inadequate. The new trend is open care for old people within the community which is an option that Greece has embraced with relevant directives. The following programmes have been implemented in order to facilitate a decent life in the community for old people (Ministry of Health and Welfare, 2003):

- Open Care Centres: they are financed by the state and operated by the local authorities. It provides a range of services: psychosocial support, nursing and medical care, physiotherapy, health education and prevention of disease activities.
- Home Help: this programme is also financed by the state and operated by the local authorities. It targets frail and lonely old persons and aims to reduce the need for institutional care by improving their quality of life at home, and maintain their independence at their own home.
- Daily Care Centres: They are financed by the state and operated by the local authorities. They target old persons aged 65 years and older with physical or mental disorders (chronic and acute).
- Summer Camping: this programme is developed in collaboration with the Open Care Centres and provides summer vacations or spa therapy to old persons. In addition, there is a programme funded by the national Tourism



Organisation which provides seven-day holidays for old persons of low incomes.

The Ministry of Health and Welfare has also managed a number of benefits to support old persons living in the community:

- Allowance to uninsured old persons: a monthly payment which includes free medical care at the Medical Centres of the National Health System for old persons without social security.
- Social Solidarity Allowance: a monthly allowance for pensioners whose pension falls below the level (indexed in the Consumer Price index) that is considered adequate to guarantee a decent living in the community.
- Housing benefit: old persons that rent a flat with limited financial resources are eligible to the housing benefit, which means that their rent is paid directly to the owner by the Greek state.

The Greek Ministry of Health and Welfare has made significant decisions in order to reform the National Health System (Ministry of Health and Welfare, 2003) but as shown above there are still drawbacks that need to be tackled. Sissouras (1990) pointed out that historically the health system in Greece

‘moved towards operating on a de-regulated basis, breeding on an acute type of commercialisation and defying all concepts of free market and competitive practices’ (Sissouras, 1990; p 149).

The reform of the health care system with the implementation of the NHS in 1983, was expected to give a solution to the above drawbacks. But

‘the health services today still operate, by and large, under the same market and false competitive practices which seem to be strongly embedded into the system’ (Sissouras, 1990; p150).

In a later study Sissouras et al (1994) pointed out that the Greek patients continued to be unhappy with the provided national health care system (they appeared to be the most disappointed in the European Union). Patients argue that they are not provided health care that covers even their basic needs of acute care. They pointed out there

was no evaluation of the quality of care, neither in terms of quality assurance or clinical audit practices.

## **1.5 Writing in the first person**

Appropriate language use is crucial in order to establish a relationship among the writer and the readers. In addition, a thesis is a research project performed not only for research but also for academic purposes. Therefore, it needs to follow rules, regulations and trends of the academic writing as well as of the published research in journals.

A search in the internet has identified a large number of qualitative research papers that have been written in the first person (I). A hand search in qualitative journals published the last ten years (like the *Qualitative Health Research* and *Qualitative Inquiry*) revealed that the number of articles published in the first person has a very strong representation. Articles presenting personal experiences and views are mostly written in the first person, for example Belgrave et al (2002) Wolcott (2002), Vickers (2002). These three articles were chosen as examples from the literature as these are on the subject of qualitative writing. There is though a significant number of qualitative articles written in the third person (for example Crist, 2005; Tutton, 2005) published in highly regarded nursing journals like the *Journal of Advanced Nursing*.

A search in journals of other than nursing disciplines, reveals a debate regarding the use of the first and third person in research publications. As far as the academic writing is concerned there are researchers, especially in the field of linguistics, that study the use of the first person by students within the academia.

Norris (1997) and Holliday (2002) both agreed that this trend of writing in the first person is a result of the new post-modern thinking. Norris (1997) pointed out that

‘postmodern celebrates diversity and plurality; multiple voices, perspectives, truths, and meanings; tolerance for paradox, contradictions, and ambiguity; and the blurring of boundaries between research and everyday life...Postmodern research tends to feature dialogue, self-disclosure, and process rather than goals such as theory generation or direct applications for practice’ (Norris, 1997; p89).

Although the use of the first person in qualitative research is currently widely accepted and used in qualitative research, as Fullbrook (2003) also suggested, the dominance of the impersonal writing in the third person is clear due to the fact that researchers still feel the need to justify their decision to write in the first person by drawing from the relevant literature about its appropriateness. On the other hand, as Belgrave et al (2002) pointed out research is usually communicated to people that have similar interests and background but it is also communicated to people that do not share the same background, therefore our assumptions or language need to be made explicitly clear to all in order to achieve the understanding of the research.

Holliday (2002) indicated that quantitative researchers consider any interference of the researcher as contamination. On the other hand, qualitative researchers consider not only the presence of the researcher unavoidable but also a valuable resource. Norris (1997) pointed out that active writing in the first person is associated with feminine writing and it can be dismissed as ‘soft, idiosyncratic, undertheorized, individualistic, narcissistic’ (Norris, 1997, p 90). Therefore, it is expected that reporting research will be considerably different in these two different methodologies.

Hyland (2002) performed a search in the electronic resources with the help of Wordpilot 2000 (a text analysis and concordance programme) in order to determine the amount of articles where the first person pronouns were used by the authors as an author pronoun. His assumptions were that social sciences and humanities were the sciences that tended to use more often the first person pronouns and consequently authors claimed a stronger identity. This is described by Hyland (2002) as a new trend developed in opposition to the traditional writing that the writer tended to claim anonymity and did not point out any personal role.

Tang and John (1999) also identified a growing trend in using the first person in academic writing. They also mentioned that the first person can serve the purposes of explaining the structure of the essay, the research process and express the writer's opinions. Fullbrook (2003) judging from his experience as an external examiner for a master's programme, argued that the use of the third person while expressing personal experiences not only fails to involve the reader but also the writing skills of the author are questioned.

Fullbrook (2003) and Nelson and McGillion (2004) argued that writing in the first person is a valuable resource for the development of nursing knowledge. Nelson and McGillion (2004) viewed first person accounts with the use of personal pronouns as illuminating of the nursing practice. Fullbrook (2003) suggested that accepting the first person means valuing personal knowledge which is a direct result of the realisation that nursing knowledge and evidence based practise can be based not only in experiments but in researching experience of patients, of colleagues and of ourselves. He suggested also that even in experiments there is a personal element which would be beneficial to be expressed.

Holliday (2002) and Norris (1997) perceived the use of the first person as an acknowledgement of the researcher that is the author as well as the one who conducted the research. Therefore, the researcher's presence had an impact on the research in all stages from the design up to the dissemination of findings. For example, in this study, I have made decisions as far as the design of the research project is concerned that were related to personal conditions like funding and time limitations, which have to be communicated to the reader. In cases that authors, including myself, want to communicate their choices and actions, provide information on the chosen structure, and discuss the results of the research I believe that the first person can be considered appropriate (Hyland, 2002) as qualitative research and writing is an interactive and reflexive process and the third person not only makes researchers distant but even absent from the text (Holliday, 2002).



Holliday (2002) pointed out that the use of the first person allows the writer to make clear their own perspective as authors while still citing clearly the views of others.

There is the need for the appropriate use of the first person in presenting my own experiences, perceptions and arguments, theoretical sources and participants' quotations. The appropriate use of first and third person makes for an easier distinction of whose voice is being heard. This is significantly so in data analysis and interpretation of the findings.

In addition, it is a matter of rigour for the reader to be able to see my journey in both acquiring and analysing the data. Therefore, writing in the third person is construed as a barrier in the need to communicate this very personal part of the research process to the reader. The first person is therefore considered more appropriate as this paper represents my own journey. Nonetheless, it is a daunting decision to be made by novice researchers, such as myself, as Tang and John (1999) pointed out, since the use of the first person makes crystal clear that their own views are presented in their paper.

## **1.6 A comment on terminology**

In research projects, choices have to be made about how to refer to those who are involved in the research project. It is significant to make clear to the reader not only what each term means but also, if there is a debate in the literature, to explain why specific terms have been used. Moreover, it is common sense that terms chosen to be used indicate certain attitudes towards those involved.

Belgrave et al (2002) in their article about writing qualitative research, reported their experience on effective qualitative writing (accumulated while participating in a review committee which evaluated applications for small research funding), and explained that researchers cannot assume that terms used in a research project have the same meaning for both the author and the readers. They have witnessed a lot of

confusion caused by inadequate clarifications on the used terminology. Therefore, the aim of this section is to prevent such misunderstandings at an early stage.

I have given much thought to how old people participating in this study should be called. In this specific project they could be called 'participants' (they took part to the research project) or 'interviewees' (they gave interviews) or 'respondents' (they responded to the questions they were asked) by no means 'patients', 'users' or 'clients' as the research involved people living in the community and the above could not be representative terms.

In addition, a literature review in the electronic databases (Medline, CINAHL) has shown a shift from the use of the term 'people' to the use of the term 'person' (McCormack, 2004; McCormack, 2003). The term 'old people' is also used in nursing research (Ekwall, Sivberg & Hallberg, 2005; Tutton, 2005). Another term is 'elders' (Crist, 2005). 'Aged persons' and 'third age' is another way of referring (Gonos et al, 2002) in Greek bibliography. The question is which term would be more suitable to be used and why.

In the nursing literature there is a significant shift to the use of the term 'person' especially in gerontological research. McCormack (2004) in his attempt to provide an overview of gerontological nursing being person-centred argued that 'old people' were not treated as persons in the past as they were not treated as whole persons but instead an aspect of the whole person is isolated from the health care professionals. His argument is strengthened by specific examples, for example the use of the mini mental health examination of 'older people' in order to assess their decision making ability and coping in different health provision levels. This practise clearly can be viewed as devaluing patients and treating them without acknowledging their personhood.

According to McCormack (2004) putting the emphasis on the 'person' in health care represents the changing attitude of respect for the right of the patients for self-determination. Clarke et al (2003) pointed out that in countries like Great Britain

policy directives define personcentredness in the care of 'older people' and set targets to treat them as individuals and make sure that they are enabled to make their own choices.

The term 'person' has been in use for centuries. Barresi (1999) cited Boethius whom in the fifth century AD defined 'person' as an 'individual substance of a rational nature', based on the thought of an earlier philosopher, Aristotle. Historically, human kind was interested in the concept of personhood but initially it was applied not only to humans but also to the spiritual world.

Locke's definition of 'person' is the one that is most often cited when searching the literature to find out what person means. Locke defined 'person' as a thinking being that has intelligence, reason and reflection and can regard itself as itself, as the same thinking thing in various times and places (Locke, 1694/1975). According to Barresi (1999) Locke had put the foundations on scientific research on 'persons' and not on 'subjects'.

Although the term 'person' is considered a term which expresses value to people there are theories of personhood which pose a lot of difficult dilemmas. The dilemmas that are posed due to small differences among the various definitions are numerous. The problem arises from the shift of the sanctity of the human life to the sanctity of the person's life in the modern societies. Immerwarf (2000) drew the reader's attention to the case of 'people' in coma which can be viewed as an issue of cost and decide that if a 'person' in coma is not considered a 'person' according to the definition of the term consequently there is no point in preserving life.

Therefore, in my thesis I will refer to 'participants', 'respondents', 'interviewees' according to their role. In addition, I will be using the term 'old person' as it shows my intention to treat them as individuals. My intention is to see behind the preconceptions about ageing and share their experiences, views, concerns and even hopes for their future. Thus it is necessary to value their personhood.

Another issue that needs to be clarified is that in the literature it is found both 'old' and 'older' used as far as the age group is concerned. For example, there is research done that targets the 'older old' (those persons that are over 70 years old, Roberts, 2002) instead of the old as a whole. I believe that 'old' is a more inclusive term in comparison to the 'older' as the second might be associated to what is called the 'older old'.

## **1.7 Thesis structure**

This thesis started with an introduction to the research project. The background, the research question, the aims and the justification of the study were stated. The Greek context has been described in short with a referral to the care of old persons. This was considered crucial to be done in the beginning so that the reader has a rough idea about the country within the research project was performed. Issues on writing in the first person and clarifying the terms used to address those involved are also explored, in order to make terms clear to the reader. The chapter concludes with an overview of the thesis.

The second chapter constitutes a review of the literature on participation. I will attempt to investigate the literature on the meaning of participation and give a selective summary of the already accumulated knowledge on participation in general and focus on a specific age group (old persons).

The third chapter will discuss issues concerning the research design. The theoretical framework, the set of ideas, that guided my research practice in order to answer the research question, and form the ontology, epistemology and methodology of my research are going to be discussed. These construct the paradigm that I followed in order to reach the aim of this study. The qualitative research approach chosen to perform the project and the appropriateness of phenomenology will be defended. The Husserlian phenomenological approach will be also discussed, and clarifications on the use of bracketing will also be provided. In depth interviews were used for data



collection as they proved to be the appropriate method after reviewing the literature. The data analysis was performed according to Colaizzi's method although other methods were explored. Rigour and the limitations of the study are also going to be discussed. Issues in translation, and challenges in translating qualitative research is another significant issue encountered throughout this research project that needed to be addressed in detail.

The process consists of the following: ethical approval, sampling-recruitment-informed consent, selecting the setting, pilot interviews, data collection, data analysis, dissemination of the findings. Sampling and sample size will be also analysed. Data management will be described in detail. The pilot study performed will also be described.

In the fourth chapter I will present participation in nursing care as viewed by the participants of the present study. It is clear that participation is experienced with an extraordinary diversity with both negative and positive aspects. Finally, in the fifth chapter, I will outline the implications for nursing practice and provide an overview of the study.

## **1.8 Summary**

The research question of this study is the meaning of participation in nursing care for old persons living in the community in Greece, through their lived experience. The study aims to gain an understanding of the meanings given to participation in nursing care as perceived by old persons. It is hoped that the understanding gained will contribute to improving nursing practice, influencing policy planning in the health care sector within the person centred philosophy and might also serve to initiate more research in this field within the Greek context.

This chapter has given an overview of the research project and tackled issues that could cause confusion to the reader about language (the use of the first person and

the terminology). The Greek context was described for future reference. The next chapter will review the literature on participation and related issues.

## **CHAPTER 2**

### **REVIEWING THE LITERATURE**

#### **2.1 Introduction**

In this chapter, I will attempt to show how participation is presented in research projects, find out whether there is common understanding of participation among health care professionals, patients and old persons in particular. First, I will describe my literature review process so that the reader has a clear view of the strengths and weaknesses of the material presented.

Literature has shown that participation is a phenomenon that started to become increasingly significant in recent decades, thus a brief overview will be used to aid by setting the historical background of the phenomenon. In this case, it is evident in the literature that through time there has been a change in the thinking of health care professionals regarding participation, which is expressed by the use of different terminology such as ‘patient participation’, ‘user participation’ or ‘consumer participation’. I will also discuss whether participation is desirable for the public.

The concept of participation will be explored from the point of view of the participants (old persons), health care professionals and nurses. Following this, the term ‘community’ will be explored and participation in the context of community will be described, as well as the benefits and drawbacks of participation.

Factors that influence the presentation of the phenomenon will be discussed. The issues of power, choice and control in relation to participation will also be discussed as they affect the presentation of the phenomenon. Related issues such as interpersonal relations and the use of internet will also be addressed.

This review will be structured as follows:

- Overview of the literature review method
- Historical overview of patient participation
- Discussing whether participation is desirable for those involved
- Defining the concept of patient participation
- Exploring health care practitioners' views of participation
- Exploring old persons' views of patient participation
- Exploring community participation in health care
- Benefits and drawbacks of participation in nursing care
- Factors that influence participation
- Power and control in health care
- Participation and nursing care in the community, discussing the emerging relationships
- The changing face of participation
- Summary.

## **2.2 Overview of the literature review method**

Before starting the study I explored the literature in order to identify the depth of the already accumulated knowledge of participation. This has been an on-going process over the last years as, even before I started my PhD, I kept myself abreast of the latest research regarding the issue of patient participation.

I started my literature search at the end of 2001 by researching systematically all of the relevant databases available in the Library of the University of Edinburgh.

Initially, I looked for research published without a time limit by using the keywords 'patient' and 'participation'. The available databases included: CINAHL (The Cumulative Index to Nursing and Allied Health Literature), Cochrane Library, Medline (the National Library of Medicine database) and ASSIA (Applied Social Sciences Index and Abstracts, which aims to cover the needs of health and social sciences). All these were used in the beginning on a trial basis. As I continued with my research I focused on CINAHL and Medline as I found them to be the most appropriate due to their emphasis on research concerning nursing practice. CINAHL is the database which provided me with the most interesting and relevant results. Medline was used due to its relation with the International Nursing Index. Other databases like ASSIA were used on a trial basis but their results either overlapped with results obtained by CINAHL and Medline or were irrelevant.

I was interested not only in acquiring an overview of the literature over the years but also in obtaining a view of how research has developed in the area. I was amazed by the wealth of literature concerning patient participation as well as the variety of terms used interchangeably, such as 'collaboration', 'involvement', 'partnership' (Ashworth et al, 1992; Cahill, 1998) and even 'self help'.

At an earlier stage, Brearley (1990) indicated in her literature review about patient participation that there were a number of overlapping themes found in the literature but not a clear definition of patient participation. Silverman (2001), an experienced researcher, stressed the problem of confusion that can be caused by a multiple meaning of the same term or situation. Therefore, it is important to understand what participation means for those involved.

As I have already mentioned, my research concentrates on old persons and the community setting. Therefore, my literature review focused on this specific age group and setting. Initially, I expanded my search by using the overlapping terms and afterwards I refined my research by focusing on a specific age group, old persons. Finally, I explored community participation in health care using the international literature as a guide.

In addition to the search within these two databases I also hand searched available nursing journals in the University of Edinburgh Library, as there was the possibility that articles of interest might not be identified electronically if my keywords were not sensitive enough. My hand search included published papers since 1990 and I included significant papers since 1978. Participation started to gain increasing significance in the 80s, and having a whole view of the phenomenon was considered imperative, thus the literature will cover more literature than this of the last decade. This tactic proved to be very beneficial in refining my literature review, enhancing my confidence of using the correct keywords and making me fully aware of all relevant literature published in the last ten years. My initial search made me conscious of the multiple terms that can be used instead of 'participation'.

The last literature review identified more than 200,000 articles on patient participation for all types of publications (reviews, anecdotes, research, etc). The results were retrieved after searching CINAHL and Medline with the keywords 'patient', 'participation', 'collaboration', 'self-help' and 'involvement'. Additionally, the terms 'elderly', 'old people' and 'old persons' were used to direct the research towards this age group. The research was limited to research articles written in English within the last ten years. When my literature search was limited accordingly, it yielded just over 13,000 articles.

Initially I attempted to identify the papers of interest from their title. However, I soon realised that only a few papers could be excluded on this basis. Therefore, I decided to read their abstracts. The difficulty in this case was that not all of the papers identified by the literature review had abstracts that were accessible via the search engine. In addition, in some cases the abstract did not provide sufficient information to allow me to decide whether I should include the paper in my review. In such cases articles had to be fully read in order to select relevant articles to my area of interest.

The main limitation of my research strategy was the language barrier as I have already mentioned above. I limited my research to the English language, although



this was not a decision I controlled fully, due to the fact that I am not fluent in any other languages than English and Greek. Consequently, research published in other languages was not included. This means that my knowledge on participation could be considered as having a focus on knowledge accumulated in Western Europe, North America and Australia.

It is argued that non English speakers wanting to publish research face the problem of the language barrier. This can affect their ability to present well constructed arguments in comparison to native speakers. This may lead to their research not being accepted for publication (Flowerdew, 1999). It is clear that language can be a difficulty as far as publications are concerned.

Flowerdew (1999) interviewed scholars in Hong Kong from different disciplines over a three year period, up to the point of reaching saturation, in order to identify the drawbacks they faced in publishing research in English. The findings suggested that qualitative articles are more problematic as far as publication is concerned. Writers felt that they need to be fluent in the language they will write the article in, to be able to present the findings and their claims in a way which is appropriate for publication.

Panayiotou (2004) in her study used bilingual participants presented with a scenario in Greek and English adjusted in the Greek Cypriot and American reality and asked participants to describe their feelings in each of the languages. The results were very interesting as the participants expressed different emotions in the different languages although the scenarios were the same. They admitted that their feelings were different as they saw the situation described into the context of societal culture.

In addition, Panayiotou (2004) argued that emotions could be translated as linguistic meanings but it is difficult to represent their meaning, that is developed within a certain cultural environment, by a simple translation. Koskinen (2004) also argued that optimum translation is done across cultures and not languages. In the same vein, Pavlidou (2000) reported that even in telephone conversations the researcher can see

the different way of thinking among cultures. She analysed telephone conversations in Greek and German and identified differences according to national character.

My personal experience on this matter has shown that there is a considerable difficulty in writing when someone is not a native speaker, moreover when writing for academic purposes. Communicating claims, arguments, personal views and experiences is a process that needs a lot of effort and it is not always of a satisfactory level. Putting a lot of effort might not be enough. Especially in qualitative research, it needs writing skills to present an argument that will make sense for the reader through personal views and experiences and will be used to construct an argument. Several times I found myself in the position of feeling that I did not quite said what I had in my mind, that something was missing there and I could not reach out to the reader the way I intended. Thus, I needed to develop a strategy so that I could reach my aim which was reaching the necessary standard for academic writing. Having the text read by a native speaker and ask whether this made sense was actually the best option I had.

In addition to the above I have also to mention that even reading papers in English when someone is not a native speaker sometimes could result in misunderstandings. As mentioned above understanding meanings does not have to do only with the knowledge of the vocabulary but with the actual understanding of the context that this material has been written in. So, a Japanese nurse for example might write a paper and publish it in English but there is the possibility that, for example, an English, a Greek, a Cuban and a Finn for example would not understand it in exactly the same way.

Although there is the possibility of having missed some information on participation having limited the literature search due to the language barrier, I did make every effort to be aware of the already accumulated body of knowledge on participation and identify an interesting area of research, which would be a useful contribution to knowledge and enhance nursing practise.



The literature used in this thesis is selective. It is not feasible to present the whole body of knowledge on participation. I must also make clear that choices had to be made concerning which articles should be used on some occasions so that significant pieces of work would be included as well as recent publications. I have tried to provide an overview of the literature and give some insight into patient participation over a longer spectrum of time. In this chapter, part of the literature review will be presented and will be fully explored in the following chapter.

### **2.3 Historical overview of patient participation**

In order to achieve a greater understanding of the concept of patient participation and its significance for nursing care, I will attempt to provide a brief historical overview of the phenomenon. Participation is a phenomenon that has been part of the health care practise over the last decades. The concept of patient participation was included in the Declaration of Alma-Ata of the World Health Organisation (1978) and triggered a significant change in national health systems all over the world. One by one the members of the World Health Organisation embodied the concept in their directives and health care professionals did so in their practice. The central idea for the World Health Organisation was that patients were citizens and because of that they had the right and the duty to participate in their health care and the assets that determine health (Hook, 2006) It is useful to know why participation in recent years has started to acquire growing importance for health care as well as how it is expected to develop. The literature is giving some answers but there are more questions that need to be answered concerning future developments as well as how people view the phenomenon on the present.

In the past, patients were viewed as 'passive recipients of nursing care' (Biley, 1992, p 414) and when a person became sick it was assumed that this person would be entirely dependent upon health care professionals. Parsons (1957) argued that a sick person would not work or undertake activities and would rely on health care professionals in order to get well and return to routine. This theory has influenced

medical thinking as a theory that has not only been followed but has also triggered significant opposition (Cahill, 1998).

Since then a significant change has occurred, not only within health care but in society in general. Society has gradually accepted a new norm regarding autonomy and individual responsibility (Ashworth et al, 1992). There is literature which claims that many of the major causes of morbidity and mortality are lifestyle related and therefore preventable (Latter et al, 1992). Demographic trends also result in a focus on maintaining the ability to be self-reliant and maintaining health over the longer lifespan that most people can now expect, as old age is not a condition that can be cured. Therefore, according to Latter et al (1992), the proportionate increase in chronic, incurable conditions as well as the ageing population, means that individuals and their families are encouraged to participate in their own care and manage their own illnesses. This move is reflected in policy directives.

According to Coulter et al (1998), there has been an increasing enthusiasm for involving patients more closely in decisions about their health care, as patients now are able to understand that knowledge about illness and health is not the exclusive property of health care professionals. Levin-Zamir and Peterburg (2001, p 88) summarised this change in society in two words: 'health literacy'. They define health literacy as

‘the achievement of the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health’.

Moreover, Malone et al (2004) argued that the rapid growth of the internet has also had a decisive effect on patient participation due to the wealth of information that is easily accessible regarding health issues (see p 78).

Cahill (1998) in her literature review suggested that there is sufficient evidence in the literature to claim that consumerist ethos of the 70s, which affected the health care setting, and patients began to be seen as “active patients”. Paper (2002) argued that

consumerism has influenced changes as policies started to stress the importance of cost-effectiveness in health care. That meant that doctors were no longer the only ones who determined the type of care that would be provided, as other groups began to have their say. Hickey and Kipping (1998), Felton and Stickley (2004) also agreed that consumerism has played a significant role. However, they added that the notion of democratisation of the health care services, during the same period, has also played a significant role. Cahill (1998) argued that nursing has moved on from the biomedical model of nursing care to embrace a person-centred approach, which considers patient participation as an essential element of its philosophy.

In the same vein, Edwards (2000) justified why users should have an active role in their care and treatment in the modern health care reality:

‘A moral reason. Users are usually a vulnerable group, often frightened, unassertive and inarticulate.

Technical and economic factors. In order to provide the most effective interventions and treatments their views provide one measure of their usefulness; hence such views could lead to an improvement in the service and give better value for money.

Political aspect. In a democracy it is the right of citizens that publicly supported services be accountable to them and a way to achieve accountability is by participation’ (Edwards, 2000, p557).

Simpson (1997), on the other hand, pointed out that the traditional health and welfare state is still based mainly on one group of service providers making decisions for another group of service users and that as a result, the services that people experience remain paternalistic and disempowering. It is obvious that there is still the criticism that health care providers tend to give the passive sick role to their service users. Therefore, there is still a need for improvements.

Rosén et al (2001) claimed that modern health care systems cannot always provide standardised solutions to patients. This is not only because the solutions might not be acceptable to patients but also because the number of treatment alternatives is growing. Therefore, whether or not patient participation is beneficial for the patient, it will become increasingly important in health care practice. A survey was

conducted in Sweden (Rosén et al, 2001) concerning choice and participation in the primary care setting and the results showed that patients want choice of treatment, choice of primary care physician and information. There was an increased demand for information and choice among younger respondents. From this someone would assume that as the younger generation will grow older they will form a new reality of old persons that will seek an active role in health care. In addition, a new culture will be developed due to the education of the younger generation to be active patients.

The preceding literature creates a number of questions that will need to be explored regarding the future development of health care as not only people are willing to participate in their health care but there is demand for cost-effectiveness of health care services and the society may hold responsible those that become sick due to their choice of lifestyle. The implications of the above are yet to be seen and researched. At this point it is interesting to search if this phenomenon is desirable.

## **2.4 Discussing whether participation is desirable for those involved**

Patient participation can be viewed as a consequence of the growing consumerism in modern societies as well as the result of a changed ideology which claimed that participation is a right (Edwards, 2000). Others, such as Latter et al (1992) and Coulter et al (1998) attributed it to demographic changes and the shift in emphasis in health care from curing disease to preventing it and maintaining health. The above are factors or circumstances that lead to patient participation. What is left for discussion is whether participation is desirable for old persons involved as if it is not then studies on participation are not worthwhile. Obeid (2000) reported that there is data in the literature that health care staff did not support the idea of lay participation in community health care.

There is research that indicates that not every person wants to participate in health care. Funk (2003) conducted research in Canada to determine what the preferences of



long term residents were regarding bedtimes, medication, room allocation and advance directives. She also investigated whether there were any predictors for their choices. Her sample consisted of one hundred residents in six different long term care sites in Canada. Eighty two of the participants were female and eighteen of them were male. She performed structured interviews and the results were statistically analyzed. Her results indicated that a significant part of the participants did not wish to make decisions.

She reported that when it came to choosing the time that they would go to bed, 19% of the participants wanted to participate minimally or not at all and 28% preferred a joint decision. In the question of choosing medication, half of the interviewees wanted to participate minimally or not at all, while 51% preferred a joint decision. As far as the choice of a different room was concerned, 26% of the participants preferred to be minimally or not at all involved, in comparison to 50% that preferred a joint decision. Finally, regarding the choice of advance directives, 11% were in favour of having minimal or no involvement in decision-making, while 50% were in favour of a joint decision. The above numbers clearly show that there was a significant number of interviewees (approximately one in ten) who did not wish to participate. On the other hand, there was an even larger number that preferred joint decision-making in care.

Litva et al (2002) researched the degree to which the public was willing to be involved in decision-making in health care in Great Britain. They conducted eight focus group interviews, of which four consisted of randomly selected persons, one of persons related to a health care organization and three of persons from three different organizations that were not related to health care. Then they conducted nineteen interviews in order to explore the issues that emerged in the focus group interviews in more depth. Initially, they used focus groups to identify which issues were of interest to the community and discuss these issues. Then they used the individual interviews to elucidate those results. They made it possible to grasp not only the breadth, but also the depth of the issue under investigation. Although their study was



not directly concerned with nursing care it provided a useful insight into the desirable degree of involvement.

The main conclusion of this study was that people's willingness to participate varied. Respondents tended to be more willing to participate in a health care system level and in programmes that were operated by health care professionals. On the other hand, they were not willing to take part in decision-making at a patient level. It was apparent that they wanted to be consulted but not responsible for the decisions that had to be taken. The study participants thought that they could provide useful insights that would improve the health care system and the programs provided. In case their feedback was not taken into consideration by health care authorities, they wanted proof that they had been heard and the rationale behind the decision to be explained to them.

Doherty and Doherty (2005) investigated the willingness of patients to participate in decision-making and what factors influenced them, in a hospital setting in Great Britain. They performed a small phenomenological study that followed the interpretative approach. In addition, participants were asked to fill in a two question questionnaire (one question regarding the doctor and the other the nurse). This questionnaire used the autonomy preference index that allowed the participant to choose from a variety of choices ranging from the patient holding complete control to the doctor or nurse having complete control. This research indicated that patients did not hold an active role. They preferred a passive or collaborative role in the decision-making process. There was however, a feeling of dissatisfaction and disempowerment that followed the passive attitude towards health care.

The participants consistently reported that information giving was poor. This was considered a direct result of inadequate communication between patients and doctors and nurses. Patients felt that they were not given the time or the opportunity to ask questions and they reported inadequate team work that resulted in health professionals not being informed about the progress of the patient's condition.

Moreover, some patients attributed this phenomenon to the small numbers of nursing staff that were insufficient to cope with the patients' care demands adequately.

One of the significant aspects of this study was the demonstration of inadequacy of clinical descriptions in researching the issue of participation. The comparison of responses that patients gave in the questionnaire and during the interviews showed that respondents tended to present themselves as more active in the questionnaire while during the interviews they described a more passive attitude. Although the sample was small, the study provided an interesting insight into the factors that could influence participation in health care such as power relationships and autonomy.

## **2.5 Defining the concept of participation**

The concept of patient participation is widely used in the health care context as well as in policy documents concerning health care provision. However, there is no clear definition of the term. Researchers who deal with the issue of participation mention that it is a term that is used with the same meaning as 'patient collaboration', 'patient involvement', 'patient partnership' (Ashworth et al, 1992; Cahill, 1998) and even 'self help'. Cahill (1998) in her literature review pointed out that researchers should be careful when they attempt to generalize views or findings regarding patient participation in health care. There are considerable differences due to the variety of approaches to participation (Beresford, 2005) adopted by different health care systems which in result affect the manifestation of the phenomenon of participation.

As far as the meaning of the concept is concerned, Brearley (1990) in her literature review about patient participation made clear that there were a number of overlapping themes found in the literature but not a clear definition of patient participation. Her claim is still widely accepted by researchers writing about participation. Therefore, it is significant to attempt to clarify the term participation in order to avoid confusion for readers.

The term 'participation' is frequently accompanied by nouns such as 'patients', 'health care consumers' or 'users'. As discussed in the previous section, historically the change from the sick role to that of a consumer has had an impact on the terminology used by nurses researching participation. Cowie (1990) gave the following dictionary definition for a patient, a consumer and a user:

'patient is a person who is receiving medical treatment or a person who is registered with a doctor, dentist etc and is treated by him when necessary' (Cowie, 1990, p 906); 'consumer is a person who buys goods or uses services' (Cowie, 1990, p 252); 'user is a person or thing that uses' (Cowie, 1990, p 1407).

The preceding dictionary definitions are quite narrow in view of the different approaches of participation as described by Beresford (2005). Beresford (2005) argued that there are two main approaches regarding participation, the first is the managerialist/consumerist approach that focuses on information gathering regarding services and their provision and the second is the democratic approach that focuses on people's lives and their improvement, moreover people believe that they need to have more say about services to have the most out of them. The main difference between these two approaches is that in the first case there is no redistribution of power while in the second case redistribution of power is the focus of the approach. In the literature regarding participation it is not always clear which is the writers approach. Nonetheless the meaning of a patient, consumer and user is a wide issue that cannot be fully explored in this thesis because its focus is on participation. Thus, papers with any of the above terms will be included in the literature review.

Bearing in mind the diversity of theories that were developed around the role of the person in relation to health care I decided to include all articles regardless of theoretical background. In addition, I need to clarify that when I use the term 'patient' I do not necessarily attribute the sick role to a person.

Participation is a concept widely used in nursing. Reading the literature about the term 'concept' itself, I became aware of the significance of concept analysis in nursing. There are nurse theorists who see concept analysis as the cornerstone of

further development of nursing by bringing together practice and research (Cahill, 1996; Duncan, Cloutier and Bailey, 2007). According to Penrod and Humpsey (2005; p404), concepts are 'empirically-based constructions of reality or truth' and they can be described through a systematic process. This process of describing a concept is called concept analysis. My reading about the nature of the term concept made me aware of a wide variety of approaches that exist in order to conduct concept analysis.

According to Penrod and Humpsey (2005) there are two types of concepts: the everyday or ordinary, which describes how persons see things while being in the world; and the scientific one which describes meanings scientifically linked to form a theoretical description of a reality which is experience-based. Furthermore, they argued that concepts derived from the everyday form are not adequate for use in scientific research. On the other hand, when a scientific concept does not address all aspects of the ordinary understanding of the concept under investigation, then further research is needed to achieve a greater understanding of it.

In 1996, Cahill performed a concept analysis of participation aiming to unfold the essence of the concept within the context of nursing. Cahill (1996) used a systematic approach to overcome the problem of the overlapping terms concerning participation in the literature. Her concept analysis attempted not only to define the term but also to suggest what it is not and why.

Cahill (1996) used Walker and Avant's method, which she described and compared with others that were also widely used. Cahill (1996) described their method briefly as an eight step process:

1. Select a concept.
2. Aims of analysis.
3. Identify uses of the concept.
4. Determine defining attributes.
5. Develop model cases.
6. Construct additional cases.
7. Identify antecedents and consequences.
8. Define empirical referents' (Cahill, 1996, p 562).



Cahill (1996) in her concept analysis argued that there is a hierarchical relationship among the concepts of patient involvement/collaboration, patient partnership and patient participation, although other researchers have claimed that these terms are used interchangeably and have an overlapping meaning. According to Cahill (1996), they can be represented with a pyramid. She argued that patient involvement and collaboration represent the basis of the pyramid as her research of the literature made apparent existing differences among the terms mentioned above and the term of participation.

Furthermore, she argued that patient involvement is an one-way process that involves delegated tasks, related to a patient's condition, that do not demand complex intellectual tasks such as decision-making to be undertaken. Therefore, information and knowledge required are limited. Patient collaboration is, on the other hand, focused on intellectual tasks. Patient collaboration was considered by Cahill (1996) as a precursor of patient participation and it

‘is described as a process which stresses joint involvement in intellectual activities’ (Cahill, 1996, p 568).

Patient participation is considered to be on a higher hierarchical relationship in comparison to patient involvement and collaboration and is considered to precede patient partnership, which is an ideal that needs to be achieved rather than a usual nursing practice. Patient partnership is a step further than patient participation, which Cahill (1998) mentioned as a goal that health care professionals should aim for and

‘demands a working association between two people in a joint venture which is based upon a contract which may be verbal or written and which may have risks and benefits’ (Cahill, 1998, p 568).

Although her article is significant as it attempts to provide a concept analysis of the term in a systematic way, her arguments are not based on sufficient examples from the literature. Therefore the reader is left in doubt as to whether her analysis was



based on a large body of existing literature on the subject or a selective one that would support personal opinions.

However, the main criticism of her method is that it follows the logical positivism movement (according to Polit and Tatano Beck, 2004, this is the philosophical theory which puts the emphasis on the rational and scientific), which means that a concept is viewed within boundaries that are well-defined. The question that arises is whether this approach can be relevant to nursing as nursing science is associated with concepts that involve complex and changing issues (Penrod and Humpsey, 2005). In this case participation seems to be one of these complex and changing issues that cannot really be totally grasped as an experience. As shown earlier in the historical overview (see p 28-30), it still is expected to change following the changes in people's thinking.

Thus, the conceptual analysis is not enough, if it was we all would have a commonly accepted understanding of the term. In fact, as far as the clarification of the concept of participation is concerned there are various other approaches found in the literature. Ashworth et al (1992, p 1431) referred to a dictionary definition where participation is said to be

‘taking part, association, or sharing with others in some action or matter’.

In her concept analysis, Cahill (1996) also referred to a dictionary definition. Although she demonstrated a concept analysis she started with the dictionary definition which is often the resource we turn to first when attempting to understand meanings.

Ashworth et al's (1992) reference to a dictionary definition is justified by their statement that it can be considered as a starting point in the process of unfolding the essence of the phenomenon of participation. Furthermore, other researchers like Cahill (1998) in her literature review pointed out that a dictionary definition has the benefits of being brief and well-defined.

Nevertheless, there is the criticism as to how the dictionary definition is going to contribute to the aim that they (Ashworth et al, 1992) set, as it is a rigid and static view of the phenomenon that manifests itself in such a variety of ways within the health care context. The authors stated that if patient participation is going to guide caring practice for nurses then there is a need to unfold its essence. Therefore, they suggested the use of phenomenology as a method that can at least provide carers with the understanding of what participation means for the participants.

In addition, Brearley (1990) performed an extensive literature review focused on the active patients model and suggested that participation is

‘the process that a person can function on his or her own behalf in the maintenance and promotion of health, the prevention of disease, the detection, treatment and care of illness, and adaptation to continuing disability. Participation may occur independently of, or within, the existing system of care, and extends to activities performed by individuals on behalf of others and in the planning, management and evaluation of health care provision’ (Brearley, 1990, p2).

She described the active patient as one who does not accept a passive role and will seek responsibility for their own care. This means that the patient asks questions, requests explanations and expresses preferences and opinions and expects these to be heard (Brearley, 1990). This approach could however be criticised for not including all relevant issues when considering the meaning of the term as there are people that might not be represented by the active patient model that was developed at an earlier stage.

Furthermore, Brownlea (1987) defined participation as getting involved or being allowed to become involved in a decision-making process or the delivery of a service or the evaluation of a service, or becoming one of a number of people consulted on an issue or matter. This definition of participation includes the decision-making process, which is an important element of the concept.

Peplau (1988) claimed that participation is a psychosocial skill made easy by a nurse who accepted and respected the patient as a person capable of making choices. However, there is evidence that nurses do not have a common understanding of the concept of patient participation in nursing practice (Jewell, 1994). Therefore, it is difficult to implement it systematically into nursing practice as Peplau's definition implies.

Jewell (1994) performed a small ethnographic research project with a sample consisting of four primary nurses from two care rehabilitation wards for old persons. Her aim was to discover their perceptions about patient participation and the role they played in the process. Although the participants consistently expressed their belief that patient centred care was valuable, they did not give a consistent answer about what participation meant to them. Despite the fact that her sample was small, it is indicative of the variety of meanings that the term 'participation' is associated with. It brought to the attention of nurses the difficulty in finding a commonly used meaning of the term. In the same vein, Cahill (1998), in her literature review about patient participation, argued that as far as participation is concerned, the concept still needs to be defined in a standardized way in order to make sure that both health professionals and patients mean the same thing when they refer to it. The literature review has shown that this is still the case.

## **2.6 Exploring health care practitioners' views on participation**

It is obvious from the discussion in the previous section that nurse practitioners can have their own views about participation that do not necessarily agree with patients' views. In the past nurses have been accused of not having an adequate understanding of patient participation which could result in patients having unidentified and unmet needs (Ashworth et al, 1992). This stresses the importance of clarifying what participation means for both patients and health care professionals. There has been research conducted that attempted to address these issues and offer a clearer view of them.

Sahlsten et al's (2005) study of Swedish nurses' perceptions attempted to clarify the meaning of the term 'patient participation' in nursing care. They used grounded theory, collecting the data with seven focus group interviews. Their informants were predominantly women with between 2 and 38 years of work experience. They analyzed the data using the constant comparative analysis method which generated four sub core categories deriving from a wider range of categories.

Their findings consist of several categories, firstly the interpersonal procedure (Sahlsten et al, 2005; p37) which is based on communication and interplay in order to achieve interaction among the nurse and the patient. Communication is considered as the basis of participation created through contact and discussion with the patients. Interplay is considered to be the personal involvement of nurses with the patients and is pursued by daring to express themselves, inviting the patients to be involved with self-care, confirming to the patients that they are available to support them and that they are listening to them and lastly, by expecting the patient to be ready to participate.

Then, they referred to the therapeutic approach (Sahlsten et al, 2005; p37) which they thought that was based on the development of a 'therapeutic relationship', this is a requirement of patient participation. A 'therapeutic relationship' is based on the nurse having achieved self-knowledge and professionalism and being able to provide reassurance and empathy to the patients.

In addition, they mention the 'focus on resources' (Sahlsten et al, 2005; p37) which they consider as involving constant discussion with the patient to identify resources relevant to the arising needs and considered to be based on the exchange of information and knowledge between the nurse and the patient. The nurse needs to know what the patients know about their condition and how they perceive themselves in order to provide the knowledge and information needed on an individual level. Nurses also need to know what the patient's expectations are and also take into consideration the person's cultural background.



Another theme they identified was called as 'opportunities for influence' (Sahlsten et al, 2005; p37) which was defined as an intentional interactive relationship initiated by the nurse in order to provide the patient with opportunities to influence the development of the caring process. It is based, first of all, on information exchange which can lead to the ability to make informed choices and decisions. Ultimately there is a joint responsibility which might vary from situation to situation and from person to person. It is stated by the nursing staff that when a patient takes on responsibility they feel that reciprocal participation has been achieved. The mutual nature of participation is also highlighted in earlier research (Ashworth et al, 1992). What is not clear is the meaning of the term 'therapeutic' that is used in this paper.

The above results are definitely valuable for the advancement of nursing knowledge and enhancement of nursing practice. However, there is the consideration of whether the results could be generalisable as a study which has been performed strictly on a hospital setting and in somatic care in particular. I came to realize, during this literature review, that participation can manifest itself in a variety of ways even in the same context.

In the same vein, Wellard et al (2003) investigated what consumer participation meant for nurses working in acute care settings in Australia with a qualitative interpretive study. They used three focus groups and participant observation to gather their data. The first group consisted of six nurses in their first practice year, the second focus group consisted of eight nurses with more than one year of practice and the third group consisted of six nurses that were managers or team leaders. Their participants expressed a high level of awareness regarding the value of participation and also demonstrated commitment to achieving it.

Despite this, a difference of opinion between the different focus groups was revealed. Nurses in different practice levels had a different understanding of the meaning of participation as well as how it could be implemented into practice. The most experienced participants were more supportive of the concept of participation in care.



The most experienced nurses considered participation as a process of keeping consumers fully informed in order to be able to make choices and decisions over their treatment, even their discharge; therefore, to be able to be in control. On the other hand, it was reported that nurses intentionally maintained some level of control over the care given to the consumers. The nurses that had less work experience attempted to find excuses of maintaining control such as time limitations, the most experienced nursing staff expressed the opinion that nurses intentionally maintain control over the care provided through a variety of ways such as rules and regulations (Wellard et al, 2003).

The most interesting aspect of their study was the comparison of the data collected from the focus group interviews with the data collected by participant observation. Participant observation identified a number of themes. Firstly, they argued about the 'division of labour' (Wellard et al, 2003; p 259), dividing nurses in two groups, senior and junior. Senior nurses (third focus group) are not involved in bedside care but they seem to make the decisions related to care planning in co-operation with other health care practitioners and not in co-operation with the consumers themselves. On the other hand, junior nurses delivered bedside care (first and second focus group) which was task oriented. They were performing specific tasks, like the administration of medication, and they did not involve patients in making choices or care planning. In the few cases where they did give options to patients, the choices given were narrowed by the absence of appealing alternatives. Even the time spent with the patients was task oriented and patients had no control over their care in general.

Another theme that was pointed out was the existence of communication issues (Wellard et al, 2003; p 259). They argued that lack of communication was apparent as nursing staff spent time with the patients only when specific tasks needed to be performed and no real conversation was recorded. Although nursing staff argued in their interviews that during this time they communicated with patients and they considered it a valuable interaction, their practice revealed the opposite. They even remained unresponsive to patients' attempts to communicate.

In addition, they referred to 'environmental constraints' (Wellard et al, 2003; p 260) as another limitation to patient participation that was posed by the environment over which patients had no control. First of all, the room was occupied by both male and female patients in order to maximize bed occupation. As a result, the curtains to be drawn between beds in order to maintain privacy, thus minimising the opportunities for communication among nurses and patients. Secondly, the four-bed room was noisy due to the simultaneous use of radios and televisions, making it difficult to have a private conversation. Finally, nurses controlled the level of volume or even channel selection according to their preferences.

The above study demonstrated what was already known to researchers: that interviewees might give selective information about the issue they are questioned on. In this case the additional use of observation provided the researchers with interesting results that help nurses illuminate how the phenomenon of participation is demonstrated in everyday practice in the health care setting. More research does justify claims made about the control health care professionals exercise over interactions with the patients, as will be discussed further.

As far as bedside reporting is concerned, there is more research that compares nurses' and patients' views on the subject. Timonen and Suhonen (2000) performed a questionnaire survey in Finland including both nurses and patients in order to study the views of both about this approach to participation. Their sample consisted of 118 nurses and 74 patients. They achieved a high response rate: 81 per cent in total. In addition, they used participant observation (observing 76 bedside reporting sessions).

This study also reported a difference of opinion as far as the nature of communication was concerned. Nurses considered their interaction with the patients to be more interactive than the patients themselves did. Furthermore, while nurses thought of bedside reporting as a process of information-giving involving both the patient and the nurse, the patients thought that it was predominantly used by nurses to inform themselves, as nurses. Moreover, they stressed their finding that although

almost all of the nurses felt that they were encouraging patients to participate, only half of the patients agreed with their claim.

Additionally, environmental factors such as sharing a room with other patients were considered quite disturbing by both the nurses and the patients. A considerable difference of opinion was manifested about the time spent with each patient. Patients clearly thought that the time spent with them was too short: approximately fifty per cent of the patients, in comparison to twenty five per cent of the nurses. Another interesting point was the use of jargon by nurses. It was shown that nurses use jargon more often than they think and this has implications for the patients' understanding of the situation. Both patients and nurses expressed the wish that bedside reporting should go on. This was an encouraging result as it shows that nurses are keen to find effective ways of achieving participation in the provision of nursing care. It was also evident that there is a difference on how nurses and patients perceive participation and the related practises.

At an earlier stage Jewell (1994) questioned the essence of patient participation to nurses. She conducted a small ethnographic study involving four primary nurses. Although the results can not be considered representative and the researcher does not report saturation of the findings, the study provided a useful insight in the nursing views about participation in nursing care. It is interesting to compare these findings with the previous ones as there are some common elements.

Jewell (1994) stated that there was not a common answer to the question of what patient participation meant to each of the study participants. However, all noted the importance of patient centred care, which could be actively influenced by patients when keeping nurses informed about their needs. Despite that, patients were not seen as active participants as they were not considered likely to ask questions when the opportunity arose, such as medical ward rounds. Therefore, nurses viewed participation as a process of encouraging patients to ask questions while keeping them informed and involving them in planning care and implementing it. It is

emphasized that nurses considered decision-making and keeping patients updated on their care plan to be essential elements of patient participation.

In addition, Jewell (1994) revealed that nurses considered some patients, such as older patients, patients cognitively impaired or with insufficient communication skills incapable of participating in nursing care. Nurses pointed out that, in such cases, relatives and carers were approached in order to be involved in the patient's care. It was common belief that compared with the past; patients have been playing a more active role in their nursing care over the last years. As far as the identification of a process of patient participation is concerned, the participants identified two types of process. First, the formal process which is occurring during the formal assessment in order to develop the care plans (assessment, care giving and evaluation of provided care). The patient is asked about problems that need to be addressed and this is taken into consideration for the development of the nursing care plans. Second, the informal and continuous process which is occurring whenever a nurse interacts with a patient by keeping the patient up-to-date with their nursing care, asking about their expectations and communicating these to the rest of the team to be taken into consideration when planning for their care.

Jewell (1994) pointed out that the relationship developed between the nurse and the patient, and its intimate nature, has a vital role in patient participation, no matter what the approach. All of the participants considered extensive knowledge of the patient's condition, derived directly from the patient or the family or the carers, essential in order to develop their role in patient participation. In addition, nurses did not view their role in isolation but rather as part of a wider multidisciplinary process (see p 76-78) in which each health care professional plays a significant role. Therefore, patient participation is a significant issue for all health care professionals.

Jewell's (1994) last argument pointed out that phenomena in health care cannot be viewed in isolation. Consequently in this complex matter of participation it is relevant to have a brief look at the research done in other disciplines in the health



care context. A brief literature review also identified a significant interest in participation expressed by general practitioners.

Geest et al (2005) reported on the findings accumulated after interviewing 233 general practitioners and 360 patients (over 70 years old) in 11 countries (Austria, Belgium, Denmark, France, Germany, Israel, the Netherlands, Portugal, Slovenia, Switzerland and the United Kingdom) about their views on different methods of participation. Their study presented an entirely different approach to the matter in comparison to nursing. Their positivistic approach to patient involvement, viewed as occurring through patient information leaflets and patient satisfaction questionnaires, is not common in nursing. This viewpoint represents a very narrow view of participation in comparison to the research discussed earlier in this chapter.

In addition, Brown (1999) researched the literature about the patient participation groups in general practices within the British National Health Care System. Using these groups is not a widely used model of patient participation but its use is slowly expanding and it is argued that such groups could have a significant role, especially in areas with great health care needs (Brown, 1999). According to his findings, the patient participation groups are unevenly distributed around Britain. The majority of them are initiated by a doctor and linked to large general practices. However, the majority of them have been active for less than five years and have a small number of participants ranging from 11 to 50 people. His literature review has made apparent that they operate within the World Health Organisation's suggestions that propose: Provision of services to patients on a voluntary basis (for example prescription collection services); Provision of feedback about the organization practice: for example meetings to deal with complaints and suggestion boxes; Provision of health education, even health promotion and community health development.

Brown (1999) in his literature review concluded that research in this field (general practices and not those of the public. Therefore, more research is needed to explore the issue. He also pointed out that there are other disciplines that are more sensitive in allowing persons to be heard in research projects concerning the issue of



participation and they should be taken into consideration. A multidisciplinary approach to participation is also widely accepted in nursing as already mentioned (Jewell, 1994).

The above literature has shown that a variety of opinions exists among nurses as well as health care professionals as to what participation is and how it can be achieved. It is very interesting to observe the variation in the approach to the subject by the researchers as well as the variations in its presentation. It is evident though that health care practitioners appreciate the value of participation and consider communication, exchange of information and knowledge, choice and decision-making to be vital elements of patient participation but there is a blurred view on how to put it into practise. Thus, an insight on how patients perceive and experience participation could be considered a useful starting point to improve their practise.

## **2.7 Exploring old persons' views of participation**

The literature review made apparent that there is not much research regarding the meaning of participation in nursing care for old people. There are a significant number of papers concerning older persons and the decision to resuscitate. Although this issue is not the focus of the present study, I will discuss it briefly as it is considered indicative of the changes occurring in health care regarding participation. Earlier studies such as the one conducted by Morgan et al (1994) indicated that old persons were not even asked about their preferences. Furthermore, others (Schnade and Muslim, 1989) defended the practice of excluding patients from such decisions as beneficial for the patients. Phillips and Woodward (1999) conducted research about the older person's views. They used two focus groups at a day centre to collect the data. The results were interesting as the participants expressed the opinion that individuals should be consulted in order to make a decision as to whether or not to resuscitate. This article highlighted another aspect of participation in the care of old persons, which is usually left to relatives and health care professionals. This is a

significant indication of the changing trends in health care, from a paternalistic system to one in which patients are active participants and partners in care.

Research has been carried out regarding the health needs of old persons and the effectiveness of provided care, for example: Moe & Schroll (1997) and Taylor & Ford (1989), competence and consent (Dowd & Steves, 1997; Rikkert et al, 1997; McIvor, 1999) decision-making ability (Edelstein, 2000) and who should take decisions regarding the setting for long-term care (Dalley, 2000; Criddle & Flicker, 2001), but there is a grey area concerning what participation means for old persons.

The data on participation and old persons in the health care setting, suggest that old persons want to participate in their care as long as they have the chance and it is beneficial for them, as identified in the following papers. Piercy et al (1999) conducted a research project in order to find out older patients' views about the shared decision-making program they developed (concerning patients with benign prostatic hyperplasia). They surveyed 678 participants before and after the programme and the majority of the participants were interested in obtaining information about their condition and participated actively in the decision-making process. The study showed that participation enhanced their relationship with their physician and their satisfaction. The authors did not however consider their research as part of the general literature on participation and therefore did not attempt to clarify the meaning of participation for their research project.

Sims (1999) conducted a cross-sectional study with in-depth interviews of 49 old patients with hypertension, examining if these patients wanted to participate in the management of their condition and which factors could potentially influence their decision. More than half of the interviewees (55 per cent) wanted to participate in the management of their hypertension. They also requested information but they had no choice of how their blood pressure would be looked after. Again, in this article the researcher was concerned about the preferences of old persons as far as participation was concerned.

In her introduction (Sims, 1999) Sims clarified what participation meant to the researcher. She referred to a definition that was used by an earlier scientist published in the mid-80s and also to the Alma-Ata Declaration and policy directives published by the British government. The views of the patients concerning the meaning of the term were not taken into consideration in this article. This research paper, published in the Journal of Patient Education and Counselling, is indicative of the rigid views of health care practitioners who are expected to implement participation in health care. Moreover, the definition of the term 'participation' that is used by the author can be considered too general or even outdated considering that it was formed at an earlier stage. This lack of clarity about the terms used in the research question, especially a term about which so much discussion exists in the literature, weakens the results of this research project and underlines the importance of defining the terms.

More recently, Tutton (2005) conducted an action research study aiming to illuminate the meaning of participation for older persons and their health care workers in the hospital setting. She was aware of the fact that patients and health care workers did not share a common understanding of the term. She claimed that nurses have little knowledge about how patients and staff view participation and how it is implemented into practice. On the other hand, she claimed that it is known that health care professionals tend to exercise control over their interactions with patients.

Although she managed to obtain satisfactory feedback from the participating personnel by using in-depth interviewing, her method proved to be inadequate as a data collection method for the old persons that participated. She attributed this to their frailty and in some cases their inability to communicate effectively. Her data were collected in four phases in a time period of just over a year. In the first phase she used focus groups and qualitative interviews in order to collect the data. She decided to analyze patient data separately and then integrate the results from both the staff's and the patients' responses, in order to identify themes that describe the phenomenon.

She identified a number of themes. Firstly, the nature of participation was discussed, this included decision-making, patient condition, personality and experiences (analyzed further as feeling grateful, fitting in and struggling). The next theme was the time which was characterised by staff shortages and organizational concerns. Then, the interpersonal relationships were discussed this includes further categories of getting to know, time, acceptance, dignity, sharing of self, emotions that are strongly felt which include aggression, encouragers and emotional work. Another theme that was pointed out was teamwork described as the philosophy shared by the team and support. Finally the environment, this includes the categories of living in a group and activities performed.

In brief, the above results made apparent the nurses' struggle to achieve participation when caring for patients with verbal communication problems within an unhelpful environment, with insufficient time and team co-operation difficulties. On the other hand, findings showed that patients were committed to dealing with their ill-health, fit in whenever and wherever possible and expressed their gratitude for the care they received.

As her research (Tutton, 2005) progressed further, by feeding the results back to the respondents and taking into consideration their feedback, she tried to develop new practices based on the results provided by the first stage of the research project. Then, after another set of interviews, she developed four further themes that underline the many aspects of participation as well as how participation can be used into nursing practise.

The first theme that was reported was 'facilitation' (Tutton, 2005, p 146) which referred to the style and strategies used in order to achieve facilitation of participation. Secondly, 'partnership' (Tutton, 2005, p 146) which was broken down to the categories of respect, trauma and negotiation. It involved the development of a relationship that could initiate participation. A third theme that was identified was the 'understanding of the person' (Tutton, 2005, p 146) which included the categories of personal history, connecting with the person, getting to know the person,



understanding the illness and dependence. This could be perceived as a process that could lead to the understanding of the whole person that the nurse was caring for.

The last theme was the 'emotional work' (Tutton, 2005, p 146) categorized as acceptance, using positive emotions and working with strong emotions. These were considered essential elements of achieving an emotional connection with the person they were caring for. What is interesting in this study is that one can have a view of what participation meant to old persons and health care workers and then is given a glimpse of what happens when someone tried to change nursing practise in relation to participation. This paper, has the significant aspect of taking into consideration the meaning of participation for old persons and health care practitioners in the provision of health care. The results were interesting and it obviously benefits nursing practice.

Another aspect of old persons' participation was revealed in a report about a project in a rural Scottish area. Age Concern Scotland developed a project in Fife (Barnes & Bennett, 1998) in order to enable older people, who could not leave their homes without assistance, to meet in order to express their needs and experiences. They went on to evaluate the project. This research program gave me an interesting insight into old persons' perceptions as far as the health services were concerned. The participants became involved in the development of health services, due to the fact that they were given the opportunity to express themselves. The results were interesting as the participants perceived their participation as a positive experience that enhanced their social lives, boosted their self-esteem and helped them learn from one another. However, they did not report any increased capacity to control their lives.

McCabe et al (2000) attempted to investigate how older persons could be involved in determining their needs in the health care setting. They used three focus groups sessions to explore older users' opinions and health and social care needs. The conclusion they reached was that there is evidence that local communities can be involved in the development of their local services. However, the study lacks a clear



explanation about what involvement means for old persons, therefore it could be argued that this research lacks conceptual clarity.

Andrews et al (2004) claimed that the focus on the involvement of old people, especially in the development of social and health services, should be increased. They justified their claim by highlighting research that argued that old persons' use of hospital services for example was excessive and even inappropriate. Furthermore, they identified literature that presented old persons as marginalized. Jewell (1994) for example, reported that nursing staff thought that not all old patients could be involved in decision-making. They justified their opinions by explaining that old age can cause confusion and communication difficulties. Moreover, they argued that not being involved was to patients' benefit as it protected them from the traumatizing experience of having to make a decision.

On the contrary, Feldman (1999) reported health care as an essential element of old persons' everyday lives and central to maintaining their autonomy and independence. In her paper, she presented findings derived from narratives and autobiographies of a group of older women. Her results provided a very useful insight into how persons experience the process of growing older and living with culturally rooted stereotypes about old age. As far as health care was concerned, participants expressed the fear of losing their independence because of sickness. The participants had experienced traumatizing behaviour which implied that growing old was a process of decline associated with increasing need for medical care. They said that they valued information giving and being involved in decision-making.

On the other hand, there are studies that report high levels of involvement of old persons in decision-making. Roberts (2002) explored participation of older persons in their discharge from hospital. Her article reported results accumulated by a study combining both qualitative and quantitative approaches. She gathered her data from 260 questionnaires and combined them with the results of 30 semi-structured interviews. Her questionnaire response rate was 50 per cent, which means that although her results are significant, they might represent a group of patients with

common characteristics, and do not include all different groups and consequently all views.

Her study focused on the period of patients' discharge and immediately after and provided encouraging results. In general, participants felt that they were involved in the process of decision-making. On the other hand, there were significant findings that presented the old persons as preferring to maintain a passive role as patients, as in their interviews they said that they accepted the expertise and authority of health care professionals. Therefore, for them participation had a limited meaning and they tended to rely on doctors for decisions regarding their discharge. As discussed in the historical overview of participation, such groups tend to demonstrate the sick role as described by Parsons (1957).

Lookinland and Anson (1995) reviewed the literature in order to identify ageist attitudes demonstrated by health care staff. Furthermore, they performed a survey to determine factors that contributed to the ageist perceptions and the implications they have for elderly care. Ageism has been defined as a widespread perception in society, which is characterised by biased, unfair and one-sided perceptions about a group of members of society based only on age. Moreover, literature presents old age as the gradual loss of abilities and energy accompanied by disease (Lookinland and Anson, 1995). In modern societies, persons older than sixty five years old are pensioners and because of that they are considered a homogenous group that are approaching the end of their lives.

Lookinland and Anson employed a convenience sample of 82 full-time nurses and 68 students studying a regional occupational program. They were given Kogan's Attitude Toward Old People Scale to fill in. This consisted of two sections that included demographic variables (first section) and statements concerning both positive and negative attitudes towards old age and six unrelated statements to minimize self-biased responses (second section).

Convenience or volunteer sampling is described by researchers such as Parahoo (1997) and Polit and Tattano Beck (2004) as one in which participants volunteer to participate in a research project. It is considered a weak sampling method because the researcher has little control over the selection process which can result in a sample that might not provide rich data. In addition, in cases where a captive population (one that is confined in a controlled environment such as students in a school or patients in a ward) is invited to volunteer there is always the question of whether the participants feel obliged to take part. Another issue is the issue of anonymity and confidentiality of the data that participants might have doubts about and which in turn might influence the data. The participants might say what they think the researcher wants to hear. Furthermore, Parahoo (1997) claimed that volunteers could belong to a group with common characteristics. Therefore, such a study will not explore all aspects of the issue under investigation.

Lookinland and Anson (1995) achieved a response rate of 91 per cent for the health care students and 74 per cent for the registered nurses. Their sample falls in the category of captive population that was discussed earlier and thus raises concerns about the acquired data. The respondents used a Likert scale to indicate the level of agreement or disagreement with the provided statements. The results of this study show that negative perceptions towards old persons were associated with the exposure to old persons suffering from ill health. The results deriving from the students' responses implied that future health care staff may have more negative attitudes towards old persons in comparison to the present day staff. What is interesting is that nurses in general reported feelings of rejection of the elderly, who are marginalized as a homogenous group.

The researchers then compared their results to those of earlier studies and came to the conclusion that nurses become increasingly influenced by ageism and gradually become more negative towards old persons. This has significant implications for nursing practice as it suggested that in the future fewer nurses will be interested in working in elderly care, whilst the population of old persons will grow larger and older (Lookinland and Anson, 1995). In research in which participants are asked

about their attitudes, we need to keep in mind that they might not tell the whole truth but say what they think they are expected to say. Bearing that in mind, the above results should seriously concern health care practitioners.

In the same vein, Bernard (1998) performed an exploratory study to investigate the relationship between women who are old and those who are growing older from both a personal and professional point of view. It has been reported in literature that women make up the majority of nurses (Lookinland and Anson, 1995) and as Bernard (1998) pointed out they also represent the majority of the older population. She claimed that women in particular expressed a need to become aware of their own perceptions about their own ageing process and old age in general, in order to be able to provide nursing care that will empower old women and therefore allow them to participate in care. Although her approach is interesting, her report consists of an inadequate literature review and a brief analysis and presentation of her findings, resulting in a weak argument.

Philp (2001), in his literature review about maintaining the dignity and autonomy of older persons in the health care context, claimed that the literature suggested that dignity and autonomy of the older patients are undermined in health care settings. This results in insensitivity towards their needs and desires, lack of information giving and therefore no opportunity to make informed choices. He reported that these are the findings of surveys conducted mainly by older persons' advocacy groups. This literature review makes evident the significance of researching old persons' views. Especially about the phenomenon of participation that are expected to have an active role.

It was clear from this literature review that the meaning of participation in nursing care for old persons needs to be explored as it is not yet clearly defined. Only recently researchers have started to investigate the meaning of participation for this age group. Thus, old persons' views and perceptions regarding participation need to be explored. Even though, there is the criticism that health care professionals may hold ageist attitudes there is the need of investigating the phenomenon for this age



group separately. If we are to tackle ageism we need to hear their voice and stop assuming that we know better.

## **2.8 Exploring community participation in health care**

This study took place in the community. I have already discussed participation and its meaning as researchers of practitioners and patients/health care users view it. What was evident from the literature review was that community was a setting in which participation was practised. Therefore, it is considered appropriate to define the term 'community' and discuss participation in the community in order to illuminate all aspects of the issue.

The concept of community participation in health care started to play a significant role in the beginning of the 1970s and was further formalized by the Declaration of Alma-Ata imposed by the World Health Organisation (Zakus and Lysack, 1998). The main aim of the Declaration of Alma-Ata was to raise awareness of the inadequacy of hospital centred care to achieve health in the modern world. Community participation was presented as the step forward that would help modern states to solve significant health care problems. Nonetheless, there is still the question of whether community participation has proved to be the ideal that was initially expected (Zakus and Lysack, 1998).

A literature review by Zakus and Lysack (1998) identified the difficulty that exists in determining what the concept of community participation means in view of the lack of clarity surrounding the process of community participation, as well as the diversity of policies used in different states countries. Community participation is often used in the international health care context, but the lack of clarity regarding its meaning can prove a significant drawback in its implementation into health care practice. In this case, both terms being used here lack clarity: participation (as already discussed in the previous sections) and community.



The World Health Organisation and the World Bank do not use a systematic definition of community (Zakus and Lysack, 1998; Murthy and Klugman, 2004) in their declarations and initiatives. The notion of community can be perceived as a geographical area with well-defined boundaries or as the sense of community that people who belong to the same group can share by identifying themselves on the basis of common interests, values or identity. Consequently, a community can be an ethnic group or a health district (Zakus and Lysack, 1998). Other writers researching the issue of patient participation in the community consider community as the setting outside the hospital or any other form of health care institution (Kirk and Glendinning, 1998). In health care, 'community' has been associated with primary care (Zakus and Lysack, 1998).

Kirk and Glendinning (1998) attempted to provide an overview of the new trends in community care in association with the concept of patient participation and their implications for nursing practice. The increasing significance placed upon community participation is considered to be a result of a number of significant changes occurring in modern societies worldwide. Their paper listed the following reasons for this:

1. the increasing population of old and older persons as well as the increasing numbers of chronically ill patients,
2. the increasing cost of hospital based care that national health care systems are not able to cover, which in turn results in developing alternative practices that would cost less,
3. patient preferences (home care is becoming more popular),
4. infection control (control of hospital acquired infections),
5. minimization of the psychological impact of hospital stay to sensitive groups (such as children and old persons),
6. technological advancements that make care at home easier and more feasible,
7. the realization that palliative care can be provided at home,
8. the emphasis on providing options to health care consumers,
9. research proving evidence of faster rehabilitation, in certain cases, if the patient returns to a familiar home setting.

Consequently, there are a variety of services provided on a short or long term basis which aim to cover health care needs in the community, prevent hospitalisation and achieve earlier discharge. A literature review identifies a wide range of research published examining lay participation in care in the community setting (for example: Pridham et al, 1998; Rosén et al, 2001). What is not reported though is what the meaning of participation for people living in the community is.

Morgan (2001) in her literature review looking at community participation in health care makes a very useful contribution to a better understanding of the concept by presenting the two models of community participation that form its manifestation internationally. In the first case, community resources, including money, labour and land, are used by stakeholders to decrease the cost of health care services. A more recent type of the same approach to community participation is based on the voluntary contribution of people, as a result of free and spontaneous will or as a result of effective persuasion. People contribute with personal labour or any other available personal resources to the provision of health care. The second case is that of the empowerment model, which considers communities responsible as well as accountable for diagnosis and the provision of solutions for their health care problems. Actually, someone could argue that community and how people experience it might be influenced by so many factors that make it difficult to be entirely described.

It is argued that community participation has failed to meet expectations because it has been viewed as the means that would miraculously solve existing health care problems in communities. In fact, these problems can have political, or even historical and cultural origins (see p 64-66), or they can be intensified by these factors (Morgan, 2001; Zakus and Lysack, 1998).

Keleher (2000) indicated that, for the time being, illness centred nursing care practice prevails instead of the health centred community nursing care that could be provided. That means that nurses working in the community are more in touch with nursing care required at the hospital setting (managing illness) than the community care that

should be aiming to maintain and improve health. Furthermore, Keleher (2000) claimed that public and community health nursing has been undermined and consequently neglected in comparison to acute nursing in policy making in Australia. She argued that nurses in Australia in the past were educated to work in acute nursing in hospitals but not in the community. This reality has started to change in the last years.

Research within nursing about participation in the community focuses on discharge planning and community mental health nursing (Adams, 2000; Muir-Cochrane, 2000). Researchers have been pre-occupied with issues like community care for discharged patients (Worth et al, 2000) and the monitoring and control of a variety of conditions (Wilson et al, 1998; Clark et al, 2000). Moreover, the above literature review has made evident that community as a setting poses considerable challenges for health care professionals and more research is needed not only to determine what constitutes community care but also what this means to people and improve nursing practise.

As stated earlier, there is a blurred view of what constitutes a community. For research purposes I decided to identify the community I planned to study as a health district which has geographical boundaries (municipality). Other writers researching the issue of patient participation in the community consider community as the setting outside the hospital, or any other form of health care institution (Kirk and Glendinning, 1998). In this study, community is considered to be the setting outside the hospital.

## **2.9 Benefits and drawbacks of participation in nursing care**

Cahill (1996), in her concept analysis of patient participation, summarized the consequences of patient participation as reported in the literature as follows:

‘a sense of contribution by the patient, improved nurse-patient communication and satisfaction, better patient adjustment, decreased number of complaints, feedback about services provided, patient empowerment, enhanced decision making, enriched quality of life, increased understanding and better management of care at home, diminished feeling of powerlessness, apathy and dependency, loss of clinical independence on part of nurse, emotional stress for both nurse and patient,’ (Cahill, 1996, p 568).

Roberts (2002) also reported that old person’s participation in the hospital discharge process and decision-making suggested that produced greater satisfaction and better adjustment. She performed a quantitative study that did not focus on a specific group of patients sharing the same health problem and did not clearly describe her methods but still her findings were interesting. The benefits of participation such as the improved satisfaction and the decreased number of complaints can offer a useful contribution to the Greek NHS (National Health Care System) as the Greek patients appear to be the most disappointed in Europe from the health care services provided by the NHS (Sissouras, 1994).

Shotton (2003) pointed out that although the number of old persons worldwide is on the increase, this is not reflected in the roles that they undertake within the community. She argued that old persons have obtained valuable experience through the years and their contribution could be significant for community development as they could provide us with advice based on past experiences. Therefore, participation in communities can be beneficial first of all for the community itself. In addition, it can help combat feelings of isolation and uselessness that may develop due to the lack of interaction with the other members of their community. As far as care is concerned, she argued that within a community, roles are interchangeable as the same person can be giving or receiving care depending on the situation.

Barnes and Bennett (1998) evaluated a project by Age Concern Scotland that gave the opportunity and the means for older persons to meet and exchange opinions and experiences and discuss their needs as far health and social care were concerned. Data were gathered with semi-structured interviews. Interviewees were asked to describe the impact of their experience in their everyday lives, the received services,



and being heard and valued. They were interviewed twice within a ten month interval. The results were consistent with Shotton's (2003) argument. This participation project proved beneficial for both the old persons and the health and social care professionals, as well as the community in general. The participants reported that this experience enhanced their social lives, helped them to gain knowledge and improved their self-esteem and psychological state in general. Their contribution was a very useful feedback for health and social services and the community was benefited by having services responding to their needs.

Piercy et al (1999) conducted a study in order to find out older patients' views about the shared decision-making program they developed (concerning patients with benign prostatic hyperplasia). They surveyed 678 participants before and after the programme in eight different Canadian centres using the shared decision-making program. They achieved an overall 72.3 per cent response rate, which is a significant rate. It was evident that the programme enhanced participants' relationships with their physicians and their satisfaction.

In the same vein Xu (2004) conducted a longitudinal survey to investigate the effect of patient participation in greater satisfaction with their physicians in the USA. 2167 (out of 3135) older patients were interviewed every six months over a total period of eighteen months. His results also indicated that patient satisfaction was enhanced by patient participation. Although this study, like the previous one, was performed by medics, it still gave interesting results concerning the issue under investigation.

Roberts (2002) explored participation of older persons in their discharge from the hospital. Her study reported results accumulated by a study combining both qualitative and quantitative approaches. She derived her data from 260 questionnaires and combined them with the results of 30 semi-structured interviews. Her questionnaire response rate reached 50 per cent which means that although her results are significant, they might represent a group of patients with common characteristics but does not include all different groups and consequently views. Her study focused on the period of their discharge and immediately after that and



provided encouraging results. In general participants felt that they were involved in the process of decision-making. Even though there were some respondents who preferred the passive role, on the whole, participation in the discharge process and decision-making produced greater satisfaction and better adjustment.

In the same vein, Mok (2001) in his evaluation of self-help groups reported positive outcomes. The researcher used a purposive sample and 449 valid questionnaires were filled in. The vast majority of respondents (95 per cent overall) reported that they enjoyed positive outcomes in all following categories: 'Outlook on life (more positive, hopeful, open, gregarious, confident, decisive in taking action); Personal ability (learned how: to accept others; help, maximise their strengths, appreciate others' merits etc); Emotional control (learned to care for others, be considerate); Relationship and knowledge about society' (Mok, 2001; p 121).

Billings (2000) explored community development regarding health care with a focus on the literature regarding its evaluation. She performed a literature review to explore the different approaches. Although she argued that there are a variety of approaches that were identified in the literature and which contradicted each other, she identified the empowerment of a community as a prevalent drive for its development. What is interesting is that she argued that participation in community organisations and actions is the cornerstone of empowerment on a personal level. Through participation, individuals influence the decision-making process and this process is reported to give the participants a sense of control.

Mohammadi et al (2002) investigated high blood pressure control in Iran. They pointed out that their results accumulated by a grounded theory research project could be applied to other chronic diseases. The sample consisted of patients, doctors and nurses that were involved in the management of hypertension. Their data collection methods included two open interviews (with a three week interval), field notes, participant observation, a literature review and patient records. The second interviews were performed in order to give the opportunity to participants to validate their initial statements. They constructed a Partnership Caring Theory which

included the acceptance of the need for patient participation in order to achieve blood pressure control in partnership with the doctor and nurse involved. It is evident that participation here was viewed as an essential element of the person's treatment.

However, participation in health care does not have only positive outcomes. Brearley (1990, p5) in her literature review regarding patient participation mentioned that concerns were also expressed about potential risks of user participation:

‘possible increased delay in seeking care, ill effects of self-diagnosis and self-medication, risks of conflicting advice, danger of uncontrolled and unevaluated treatment, misuse of highly technical information, alienation of professionals’.

These risks can be more important for older people due to the issues of decision-making capacity that can have deteriorated in some cases.

Lauder (2001) attempted to illuminate the concept of self-neglect in relation to self-care. His literature search revealed that self-neglect can be a conscious choice of the person or it can be a result of a limitation of self-care ability due to disease. In the context of the increasing importance of participation in health care, it poses ethical dilemmas to health care professionals. Nurses are under pressure to involve persons in care but they have to bear in mind that limitation in abilities due to ill-health can lead to the phenomenon of individuals receiving inadequate nursing care.

The overall feeling was that the positive outcomes of participation outweigh the negative ones. Furthermore, Cahill (1996) in her concept analysis pointed out that although there is a widespread belief that participation has a positive impact on those involved, there has been little research conducted by nurses to test the belief. Nurses resort to other disciplines to identify possible consequences as it is also evident in the preceding literature review. More research is needed so that nurses study the phenomenon of participation in nursing care.

## **2.10 Factors that influence participation**

Another issue concerning participation that anthropologists have raised is the significance of factors like the gender, age, ethnicity, religion, and economic status of the community members that practise participation. There is the argument that all of these have a significant effect on the implementation and manifestation of community participation (Morgan, 2001).

There is literature which claims that there are factors that influence participation. Anell et al (1997) questioned health care services' practice of treating individuals as a homogenous group and they conducted a survey in Sweden to determine whether factors such as age, education and residence influenced patients' views on participation and choice in health care. Their sample consisted of 2000 residents aged 18 and over in four different Swedish counties. They achieved an overall response rate of 68% which is noteworthy.

Age and level of education were the factors that influenced most individuals' preferences. Young individuals were eager to take an active part in participation than old individuals. Well-educated respondents were also more eager to be more active participants in their care. Another issue that was identified was that the priorities were different according to age. Old respondents were more interested in the choice of physician. This was attributed to their greater need to attend regular consultations.

Although this study is medically oriented, its findings can help nurses achieve a greater understanding of how demographic factors influence participation preferences. Further research by the same researchers focused on primary care was performed. Rosén et al (2001) conducted a survey in 13 general practices in South Sweden which confirmed the results of the previous study.

Cardol et al (2002) performed a cross-sectional study to illuminate the effect of chronic disability on participation in society and investigate related social, demographic and health factors that pose potential limitations in participation in the

Netherlands. 127 respondents (neuromuscular, rheumatoid arthritis, spinal cord injuries, stroke and fibromyalgia patients attending outpatient clinics in three rehabilitation centres) filled in the Impact on Participation and Autonomy questionnaire.

An interesting aspect of their results was that the authors compared the results from people from Dutch and non-Dutch cultural backgrounds and identified differences among the different cultures. Furthermore they pointed out that each individual is different, although the factor of emotional distress was common as a limitation for participation. This study indicated that nurses, like other health care professionals working in the community, need to address participation in the wider context in which the person is living in and not isolate nursing interventions.

Marcolongo et al (2001) in their paper discussed the issue of therapeutic patient education in Italy. They claimed that research in Italy indicated that a change was currently occurring regarding decision-making. Although Italians relied on their doctors to make choices regarding their diagnosis and treatment, they did seem to preserve their right to make the final decisions. As far as national initiatives were concerned, there was emphasis on health education but not on patient education.

Although this literature review is focused on medical issues, it is also relevant to nursing as it indicates that the tendency to participate in care is a cross-cultural and global phenomenon. In addition, these issues connect to the WHO and European Community directives that have been adopted by Italy with the increasing intent of the public to participate in care. It is an indication of how the WHO directives can make a difference internationally. I have already referred to the significance and impact of these directives as far as the European Community is concerned. It claimed that the economic policy imposed on the member states is forcing the national health systems to change their hospital-based care to home and outpatient-based ones. This indirectly forced the care recipients to take a more active part in their care. The question that arises is if this is desirable or forced on the health care recipients.

Morgan (2001) pointed out that anthropological research looking at community participation in health care has made apparent the significance of context, which he clarified as meaning both culture and politics as these construct the social reality in which the phenomenon manifests itself. There are paradigms like the one reported by Ugalde (1985), who noted that community participation implemented in Latin America was initiated by raising ideologies or politics that were present in that specific historical period.

The above papers argued that certain factors may influence participation and its perception. It is not clear though how and up to which extent this happens. It can be argued that different people may hold different views and may have lived different experiences but they may still mean the same thing when they talk about participation.

## **2.11 Power and control in health care**

Välimäki et al (2004) attempted to research the impact of information giving, behavioural involvement in decision-making, opportunities for decision-making and independence on how participants perceived their health. Their study was performed in five European countries (Finland, Scotland, Germany, Greece and Spain). The study found that information affected respondents' participation in decision-making and therefore, their independence level.

Unfortunately, this paper was vague in reporting the results and used jargon when reporting the statistics. The authors also pointed out that cultural differences between the countries involved might have influenced the data analysis and consequently the results. Despite these weaknesses, they reported strong similarities between Greece and Spain on one hand and between Finland, Germany and Scotland on the other hand. Although all countries, as members of the European Union, have much in common as far as legislation, education, ethics and nursing practice are concerned,



there is a difference detected that can be considered as a cultural difference among South and North Europe.

Culture is an issue of debate in social sciences. There is no clear definition of the term and there is a variety of approaches. The exact meaning depends on the approach.

Koskinen (2004, p 144) classified culture into two groups: 'the humanistic or high culture', for example art, and the 'culture in anthropological sense' that describes the way of life, for example traditions, customs and folklore.

Koopman et al (1999) conducted a cross cultural study in about sixty nations to investigate the existence of any association between societal culture, organizational culture and leadership. They attempted to include all the main cultural sections in the world. As they also pointed out, there is not a clear definition of culture common among social scientists. Therefore, they made their own in order to be able to advance their research further and develop measures that would help them achieve their objectives. They saw culture as

'shared motives, values, beliefs, identities and interpretations of significant events that result from common experiences of members of collectives and are transmitted across age generations' (Koopman et al, 1999, p 506).

They argued that culture is operationally defined by measuring the consistency of values within society and the frequency of occurring practices within families, schools, workplaces and political organizations.

Although they compared national cultures they did recognize that culture might not be confined within nations or even that a nation can consist of a multicultural society. They attempted to obtain a representative sample by including all trends known. On the European continent, 21 countries participated in the study. They divided Europe into the North/Western region, which included England, Ireland (Anglo sub-cluster), the Netherlands, Sweden, Denmark, Finland (Nordic sub-cluster), Germany, Austria

and Switzerland (Germanic sub-cluster), and the South/Eastern sector which included France, Italy, Spain, Portugal (the Latin sub-cluster), Greece, Turkey (the Near-Eastern sub-cluster), Hungary, the Czech Republic, Slovenia, Poland, Russia, Albania and Georgia (the Central and East European sub-cluster). Their results supported the division of Europe into the North/Western and South/Eastern sector culturally. They attributed the existing cultural differences partially to historical events. Language and geography were also considered significant in cultural exchange. Other factors that were considered to contribute to the cultural formation were religion, political and economical systems and technology.

In the same vein, Koskinen (2004) pointed out that cultures are not confined within natural boundaries but are rather developed within a historical and political context. Koskinen (2004) argued that cultures are political. Therefore, they have ideological origins as well as implications. Although Koskinen was mostly pre-occupied with issues in translation, and views culture from a different perspective than Koopman et al (1999), who are interested in management, they do make similar claims regarding culture.

Hofstede (2001), an experienced researcher in cultural differences, in his book comparing values, behaviours, institutions and organizations worldwide (among nations) highlighted culturally dependent differences in thinking and acting. Hofstede (2001) mentioned that the concept of 'national character' is debatable as it still contains stereotypes which might not be applicable to any individual member of the community. He considered these stereotypes half-truths as they were statistical statements and not in-depth study of the properties of the individuals. Although he questioned the truth of the 'national character' he identified differences among national societies which constituted cultural differences. He reported significant differences among various countries (among others Greece and the UK as well as the USA) in issues such as power distance (referred to the way of facing human inequality), individualism versus collectivism (referred to the integration of individuals into groups), masculinity versus femininity (referred to the emotionally differentiated roles of men and women in a society).

In this literature review there is a wide variety of research papers that are discussed and they come from a wide range of countries. As I said earlier (see p 26) the language barrier has confined my literature search in papers that are written in English that means that more papers from the English speaking countries will be included and there is a debate in the literature whether these results are relevant to countries that do not belong to this group. It still remains to be seen how similar or different results this study is going to produce in comparison to papers included in this review.

Jones (1996) questioned the relationship among autonomy and paternalism in the health care setting. Her article was very interesting as it challenged the widespread belief that these concepts are opposites and cannot co-exist in health care systems. Autonomy is presented as a straightforward term in dictionaries, defined as

‘self-determination, independence, self-rule’ (Waite, 2001, p 54),

similarly to paternalism which is defined as a

‘fatherly, protective, solicitous attitude’ (Waite, 2001, p 626).

Jones (1996) pointed out the relativity of autonomy, viewing it as a socially constructed and influenced concept within the health care context.

In nursing practice it is argued that there are situations when a health care professional will adopt the paternalistic attitude of the expert to make sure that the patient does not choose options that could prove harmful (Parsons, 1957; Simpson, 1997). Autonomy and paternalism are inversely related concepts: the more autonomy a person demonstrates, the less paternalism they are likely to have imposed on their life. Jones (1996) argued that these concepts co-exist in every aspect of our lives including health care. She argued that patients can lose their autonomy for a number of reasons, for example when a nursing practitioner thinks that that an individual does not want to know something or is not capable of understanding. She expressed

the belief that a patient admitted to the ward will often lose his or her autonomy due to a 'ritualistic display of power' (Jones, 1996). She argued that this is demonstrated by nurses wearing uniforms while patients wear night clothes, and also by discussions that take place while nurses are standing and patients are lying or sitting down.

In the same vein, Wellard et al (2003) reported that nurses intentionally maintain control over the care provided through rules and regulations. This practice minimizes autonomy and consequently participation. The most experienced nurses considered participation as a process of keeping consumers fully informed in order to be able to make choices and decisions over their treatment, even their discharge; therefore, to be able to be in control.

On the other hand, it was reported that nurses intentionally maintained some level of control over the care given to consumers. Whereas the nurses that had less work experience attempted to find excuses such as time limitations, the most experienced nursing staff expressed the opinion that nurses intentionally maintain control over the provided care through a variety of ways such as rules and regulations (Wellard et al, 2003).

The above studies were performed in a hospital setting. Morgan (2001) reviewed the literature about community participation in health care and her report of the findings supported the significance of power in relation to participation. Morgan presented the empowerment model which considers communities responsible as well as accountable for diagnosis and the provision of solutions for their health care problems.

Lothian and Philp (2001) gave an interesting insight in older people's dignity and autonomy within the health care system by presenting findings of research carried out by older persons' advocacy groups as well as health care professionals in Great Britain. Although two concepts, dignity and autonomy, have different meanings, in this article they were considered as dependent upon each other. It was argued that in



the health care setting it is difficult for older persons to preserve high self esteem and feel respectable, as well as maintaining control over their lives by making decisions and performing tasks. All these factors meant that their participation in care was limited. The main reason was the lack of information regarding their condition provided by health care professionals. As a result, they felt entirely disempowered.

Although Lothian and Philp's (2001) literature review provided useful information about old persons' views and feelings, it lacked methodological clarity as the introduction did not give details regarding the literature review method. The selection process or key words were not given. Therefore, one cannot be certain that this paper supported the writers' views and perceptions of the issue under investigation by selecting relative literature. The strength of this report is that it included studies from all settings: residential, nursing, primary and hospital setting. It also included palliative, intermediate and long term care as well as specialized geriatric and psychogeriatric care.

Suhonen et al (2003) performed a comparative study on patient autonomy in surgical care in five European countries (Finland, Spain, Greece, Germany and Scotland) from the point of view of nurses. In order to design a questionnaire appropriate for this study, they explored the same area in all of the countries involved. They wanted to make sure that it was culturally sensitive as well as effective. Their sample was predominantly comprised of women. There was a significant difference in the qualifications held by the participants. The percentage of registered nurses that participated in the study varied (73% of the Finnish sample, 66% of the Spanish sample, 45% of the Greek sample, 49% of the German sample and 74% of the Scottish sample). The Greek sample was composed of a higher percentage of enrolled nurses in comparison to the other countries that took part in the study.

The results showed that nurses felt that they did not provide enough support to patients in order to enable them to make decisions. The greatest difference was between Germany and Greece. The main reasons identified were related to the low educational level of registered nurses and their perceived low job status. In terms of



maintaining autonomy for their patients, Greek nurses appeared to be less successful than the other countries. The researchers attributed this to cultural differences or potential differences in nursing roles among the participating countries. It is not however clear if their explanations derived from their research findings or whether they attempted to provide an explanation based on their personal experiences and perceptions of the phenomenon. Although they had a high response rate and provided a detailed description of the development of their questionnaire, the presentation of their results is vague and raises more questions than answers.

Huby et al (2004) in their paper regarding planning older people's discharge from the acute hospital setting in the U.K., reported early results from their pilot study. One of their interesting findings was that older people did have the feeling that information giving was non existent or inadequate to cover their need for information and be able to make a decision regarding their discharge. Moreover, older people were very apprehensive of their 'competence' to discuss decisions with staff and they were leaving it to 'those that have the knowledge' (Huby et al, p 126).

Allen (2000) explored the issue of participation on an individual level in Great Britain. She conducted two ethnographic studies in the period 1994 to 1998, one in an urology ward and the second in a vascular ward. She reported a confusion regarding the issue of participation, stating that there was a variety of ways in which the phenomenon was demonstrated in nursing practice. It could be a simple task allocation or patient empowerment. She indicated that nurses' attitudes determined the extent of patients' participation. In the urology ward the nurses had allocated specific tasks to patients and trained them to perform them. However, they would not take into consideration patients' abilities or rights to make choices regarding medication. In the vascular ward although there were not specific tasks allocated, the nurses would take the patients' choices into consideration and would respect them. Therefore, they would show trust in patients' decision-making abilities and their knowledge about their health care condition and allow patients to have control over their care.

Allen (2000) made an interesting claim about the power control that exists in the health care settings. She indicated that information and choice about treatment was one traditional way that health care professionals maintained control over the patients. She herself had evidence that although nursing staff were willing to provide information regarding medication, they could demonstrate a defensive attitude as they considered such requests as questioning their way of thinking and their treatment decisions. This occurred in the ward where patient participation was confined to task allocation.

Although this study (Allen, 2000) was performed in Great Britain and it could be argued that it is not an international issue, there is evidence in the literature that power distribution in health care is an issue that affects patient participation in care. Henderson (2003) conducted a study in Australia to investigate views on hospital care partnership held by nurses and patients. She used a purposive sample of thirty three nurses and thirty two patients. The data collection method was a combination of in-depth interviews and task observation followed by field notes. Nurses were interviewed at their workplace while the majority of patients chose to be interviewed at their homes. This was a decision that gave more freedom to patients to discuss their views in private.

The findings were very interesting to nursing practice. Nurses considered information giving and shared decision-making as the cornerstones of patient involvement. The majority of nurses would inform the patients of the nursing interventions they would perform but they would not share their rationale and they would not give any options to the patients. Nurses preferred to decide instead of the patients. When they were asked to justify their practice, they answered that they had specialized knowledge, therefore, they were eligible to make decisions. Furthermore, they expressed the wish to maintain control in the health care context. This was evident by the fact that they controlled the interaction between themselves and the patients. Moreover, it is reported that nurses would create uncertainty to patients concerning their care as a way of maintaining control which was seen as a way of making their job easier.

Patients reported that they felt comfortable making decisions, and participated in care only when they were given adequate information. Provision of information was reported to be mostly up to the nurses, who used the technique of closed questions to avoid being asked questions by the patients. In addition, it was reported that patients were afraid that they would be punished by being offered less care if they asked too many questions. Patients reported that nurses were not even interested in listening to them and as they were unwell they finally gave in and did as they were told by doctors and nurses.

These findings are significant as they are the result of a combination of interviews and observation. The data collection methods complemented each other adding to the validity of the findings. In addition the author included the views of all involved, nurses and patients, and the sample was distributed in different wards and included both private and public financed hospitals. Furthermore, the fact that considerable differences were not reported among the different settings makes the results an issue for concern as it becomes obvious that we are not dealing with the culture of a specific setting but rather with the culture regarding nursing existent in general in nursing practice.

Muir-Cochrane (2000) studied the issues of power and control associated with the mental health nursing care provided in the Australian community context. She performed an ethnographic study using participant observation. She discovered that nurses were perceived, by both themselves and the patients, as powerful. The fact that they were healthy and had 'item-symbols' of their status (name tags, diaries, etc) played a central role in their interactions with the patients.

On the other hand, the context of the interaction, which was the patient's home, and not a formal care-giving environment, influenced the power balance in the patient's favour. In the community the patient was the host and the nurse was the visitor. The patient was in their own environment which gave them more freedom of movement and decision-making regarding issues such as the length of the visit. Although nurses

still had nursing interventions from which they could derive power, the patients maintained control over the interactions. This study which was conducted in the community, showed the existence of a different power balance in comparison to the hospital setting.

The issues of power and control are significant for participation as explained by Beresford (2005) and the distribution of power is what characterises the approach of participation (see p 34). In addition, it was pointed out in this section that information is power as far as health care is concerned and participation in nursing care cannot be expected without information sharing. Although this study is not about the issues of power and control this appeared to be of outmost importance in the discussion about participation and understanding the phenomenon. It is also clear that power and control cannot be viewed in isolation of the emerging relationships in the health care context and this is to be discussed in the next section.

## **2.12 Participation and nursing care in the community, discussing the emerging relationships**

Community care is implemented by a multiprofessional team, in which nurses are only one of the participating parts. The relationships that are developed not only between professionals and service users but between professionals themselves, and the community may be a significant element of how users view and experience participation. Therefore, issues of teamwork, communication and community relations are issues that may be a part of the phenomenon of participation in the community.

Galvin et al (1999) researched the issue of community nursing within the primary care team. They conducted an action research study to investigate, among other issues, how users saw the service provided by a general practice (in south-east



Wales), to determine the nursing care that needs to be provided in order to cover service users' needs and identify areas of practice that should be altered.

Galvin et al (1999) used a variety of data collection methods (both quantitative and qualitative): questionnaires; team workshops; focus group interviews with the service users and open-ended interviews with the general practitioners and the manager of the general practice. In addition, a reflective diary was kept and a user satisfaction survey was performed. Although this study applied a variety of data collection methods and included all professionals involved in community care provision as well as the users, it was restricted to one general practice service. Therefore, the results are representative only of this specific community.

Despite this, this research produced an interesting insight into community care. Practitioners did not have a clear understanding of each other's roles which resulted in communication problems and tension in the team. Gerrish (1999) also demonstrated that community care professionals did not have a clear view of each other's roles. Galvin et al (1999) argued that the number of nurses employed in the community had increased in recent years, as had their responsibilities, which included health promotion. This is claimed to be an 'erosion of the health visiting role' (Galvin et al, 1999; p 239) according to concerns expressed by health visitors. Some health visitors admitted that they felt that their roles were being undermined by the rest of the team and their future was not promising.

Health visitors also mentioned that community nurses would see their workload increase in the future as the shift from hospital to community care; in part because of the research project that was also performed. It was stated that a clarification of boundaries was required for specialized nurses. In addition, it was indicated that community nurses do need to be educated accordingly in order to be able to cover community needs. This implied that community education was not as significant a part of the curriculum as acute nursing (Galvin et al, 1999).



The issue of teamwork has been an issue of concern for community nurses. Gerrish (1999) attempted to evaluate what nurses offer to community care in Great Britain especially after the implementation of the integrated nursing team. She performed twenty four in-depth interviews with the general practitioner, managers and the team facilitators of the general practices. The next step was to perform six focus group interviews (one focus group interview for each team). The same topics were covered in both the individual and focus group interviews. Therefore all views were investigated.

The research findings indicated that successful integration of the nursing teams was expressed through working together as a team, communicating effectively, having their goals agree with those set by the general practice, changing their roles and being open to changes. The interviews revealed a variety of approaches to team work at all levels. Nurses themselves were divided as some were more focused on team work and others focused on individual tasks. Although this study was performed within one general practice, it may still provide an interesting insight into the issues concerning community nursing and its implementation. The most interesting results however were the ones regarding the users. In general users were satisfied although the health care professionals admitted that the provided services were not determined by the service users' needs but rather by the professional expertise that the employed professionals could offer.

The role and purpose of community nursing is still under investigation. Kvarnström and Cedersund (2006) argued that the challenge that nurses will have to face in a multiprofessional team will be to practise nursing and not be suppressed by other professionals. According to Eurostat (2002) Greece has 438.4 doctors per 100000 inhabitants in comparison to U.K. that has 174.8 per 100000. In Greece, nursing duties are defined by each hospital separately (Giannopoulou, 1999) and if you compare them with the nursing training curriculum it is apparent that nursing duties are deteriorated in a smaller field of practice in comparison to the expertise nurses acquire during their studies. Furthermore, it is pointed out that medical duties are

extended, therefore, health care services absorb a larger number of doctors in health care.

In Greece doctors have very high social status and they are highly respected. As evidence of the extent of this social phenomenon Dalla-Vorgia and Garanis (1991) mention the fact that there are almost no lawsuits against doctors in Greece. The high status of doctors has been a long tradition that cannot change overnight.

Suhonen et al (2003) in their comparative study on patient autonomy in surgical care in five European countries (Finland, Spain, Greece, Germany and Scotland) from the nurses' point of view argued that the low educational level of registered nurses in Greece, together with their perceived low work status, had a detrimental effect on nurses' ability to offer support to patients in order to help them participate in their nursing care. It is obvious that power relations among health care professionals can affect the delivery of a service and in this case participation. In the case of the Greek national health care system, there is a need to let service users express their opinions and say how they feel they are affected by the situation in the health care context.

The significance though of nurses' abilities to respond to changes and be able to work with other health care practitioners effectively is stressed in a number of pieces of research, as already discussed. More research is needed to gain a view of how health care users view this issue and how their participation is influenced.

### **2.13 Technological advancements and participation**

Malone et al (2004) examined the impact of internet use in primary care as this has become a significant source of information in Great Britain. In her article she used the phrase 'changing boundaries in primary care'. Although one can debate whether this is a politically correct statement, it does reflect the impact in everyday practice that the easily accessible information reached through the world wide web has had on health care.

Malone et al (2004) performed a postal survey that was followed by in-depth interviews with eight health care professionals (general practitioners, nurses and other non-specified health care practitioners). 74 per cent of those approached replied. It was evident that the number of cases attended that used the internet was small, at 5 per cent, but this is clearly expected to rise in the future. Another interesting result of this research was that health care professionals did not favour the use of the internet by people to make a diagnosis and investigate potential treatments. On the other hand this was considered positive for patients who had already been diagnosed.

This study identified a phenomenon that is set to pose considerable challenges to health care professionals as their expert opinions will be challenged by people who can easily obtain expert information via the internet. This has the potential to challenge the existing power relations established within the health care context. In addition it could play a major role in the development of participation in nursing care especially in the community. The study was limited to reporting health care professionals' views and it lacks demographics of the patients using the internet. This would be a useful contribution as future expectations would then be evident.

Levin-Zamir and Peterburg (2001) claimed that in the future a high demand for quality health care and limited resources will pose considerable challenges for health care professionals. They saw the development of partnership among health care professionals, the patients and their families as inevitable. Therefore, national health care systems should invest in health literacy. They made three suggestions about how this could be achieved: firstly, that appropriate tools should be created so that the public is informed through the media and the internet; secondly, that health care professionals should be trained to provide information and lastly that continuous monitoring of the sources of information should be the responsibility of both health care professionals and the public.

Their study was performed in Israel and they investigated ways of information access, training of health care professionals, the relationship developed between them and the public and ways of assessing health literacy. They tried to apply their aspect in the diabetic self-management case. What is significant in this project is that it is a rare attempt to investigate the issue of people obtaining information through a variety of sources other than health care professionals and use these sources so that health care professionals can improve their practice and assess the whole process. Because this study is confined to one country, more research is needed.

One can argue that as technology is progressing, change is influencing health care as well as the phenomenon of participation. Easy and fast access to information that in the past were the exclusive property of the specialist may play a significant role in future developments for participation.

## **2.14 Social capital and its relation to community participation**

There are studies that have attempted to determine whether old persons prefer to stay in the community and participate in their care or their relative's care in order to achieve that. The results showed that the majority were in favour of staying at home. Nolan and Dellasega (1999) conducted structured interviews by developing the Caregiver Information Form and the Placement Response Scale. In addition, they performed a number of open-ended interviews in the USA and the UK. Their aim was to discover the experiences of family carers after placing their relative in a nursing home. Although they recognized the increasing need for nursing homes, the significance of continuing family involvement is stressed. The study also revealed that participants viewed the decision to place a loved one in a nursing home as a difficult decision to be made with a long-term impact for all involved.

It is argued that community services can vary according to the family and social support that a person receives in the community. In addition, policy makers have begun to realize that a shift from acute health care provision to community care is



necessary. This is facilitated by the advances in both medical and nursing practice. It has however become a necessity due to the increasing demand for quality health care services while resources remain limited (Tinsley, 1998).

Kirk and Glendinning (1998) claimed that formal and informal nursing care are set to change dramatically due to the shift of hospital care to community (home) focused care. Health and social care directives in Great Britain have a pivotal role in this change. However, these directives are in turn based on WHO directives that have a worldwide influence. Therefore, their claims may well be valid for any other country that has adopted the same WHO directives, such as Greece. Although there is an increasing incidence of informal carers taking over areas of formal care-giving, appropriate support networks are not in place. Therefore, questions regarding the benefits and the drawbacks of this situation arise. The authors mention that there are concerns about whether this practice is ethical at all times and whether there is sufficient support provided to users. Whilst their concerns are valid, there is a need for more research to address the issue in more depth.

Cho (2005) carried out an interview survey at a national level in Korea to investigate if old persons were prepared to receive nursing care at home. The results showed that 52 per cent of the respondents would not use such a service, 43 per cent would use it if it was free of charge and a mere 5 per cent were eager to use it even if they were charged. Their responses differed according to their financial and family status as well as their experiences. Old persons belonging to the high income group were more eager to use the home care service when paying for it. Those living with their children, and therefore being taken care of by them, were less likely to use the service. In addition, people who already had a condition like hypertension or diabetes and had used the service again, were more likely to use nursing care at home.

Health care professionals have investigated the association between social capital and health in the community. Social capital is considered to be the social rules and relations within a society that enables the society to develop action strategies in order to achieve its goals (World Bank, 2004). Turner (2006) recommended that social



capital occurs from relationships among persons, families and communities to facilitate accessing important benefits and resources.

It is a widespread belief (Bubolz, 2001) that the family is not only the starting point for social capital but also the beneficiary and maker of the social capital. Furthermore, trust is argued to be the basis of behaving in a moral way which leads to the creation of the social capital (Kumlin and Rothstein, 2005; Bubolz, 2001). It is argued (Cowley and Hean, 2002) that it is beneficial to people to live in communities in which neighbours know and trust each other and where a cycle of support is existent (people help others knowing that they are also going to receive help in return at some other point).

Hyypä and Mäki (2003) carried out a quantitative study in Finland to examine if there was a relationship between social participation and health in the Swedish-speaking minority living there. In order to achieve this, they compared the Swedish-speaking minority with Finnish-speaking members of the community in certain isolated factors regarding social capital. They compared

‘demographic and social features, health status, health behaviour, social ties, reciprocal trust, and social engagement’ (Hyypä and Mäki, 2003, p 773).

They concluded that the Swedish-speaking community which was characterized by a strong community ethos, rich in social capital, was associated with better self-rated health. Moreover, it was demonstrated that socially active persons are more often active participants in health care. Their results were congruent with earlier results from research performed in other communities (Veenstra, 2000).

Furthermore, Looman (2004) conducted a descriptive study in order to define social capital for nurses through the experiences of family caregivers of children with chronic conditions. She performed three focus group interviews with a total of twenty three caregivers. Twenty of the participants were mothers and only three were fathers. This raises the question as to whether fathers are taking part in the care-

giving process; if not, their views might have not been represented adequately in this research project.

She recruited participants through a community-based advocacy organisation consisting of people with disabilities and their families. She contacted former users of this voluntary organisation by mail in order to recruit participants for her study. The ones that were interested in participating in the study responded, as advised, by sending back a pre-posted card. Additionally, they were interviewed in order to make sure that they were eligible to participate in the study. Their sample can be criticized as one that might not be representative of the general population. Certain advocacy groups attract a certain group of people that agree with their profile. Moreover, the geographical constraints in a small area undermine the potential of these findings to be generalisable. In addition, the findings are only relevant to this specific group of families that care for their children who suffer from chronic conditions.

However, her analysis produced interesting results that are worth mentioning as part of an attempt to specify the meaning of social capital for nurses. The concept needs to be understood in order to be able to integrate it into nursing practice in communities. Her thematic analysis identified five elements of the meaning of social capital for the participants.

Initially the 'system' (Looman, 2004; p 419) which described all forms of official organizations that form a network and work towards common objectives while taking into consideration the people who use their services. Then, 'trust' (Looman, 2004; p 420), parents did need to hear the truth from health care professionals and the system needed to be reliable when interacting with the service recipients. 'Advocacy', followed (Looman, 2004; p 421), a new element in the meaning of the concept of social capital in comparison to the already accumulated body of knowledge. Participants considered advocacy as necessary. It could be acquired within the school environment (as part of the system), parents could operate as each other's advocates, and most importantly there was the conviction that children have the right to a better life, an idea which could lead to people seeking advocacy.

Furthermore, another interesting theme is the 'common good' (Looman, 2004; p 422), parents tended to set goals that included their children as a part of the community. The researcher claimed that this was in opposition to the immediate goals that were set by health care professionals which were usually short term and directed towards improving skills and time management. Goals were set by parents in the context of maintaining a stable family environment, sharing difficulties, aiming to prepare citizens for future society and creating communities of the future.

Finally, the 'spiritual community' (Looman, 2004; p 422) characterised by spirituality and its expression by being part of a spiritual community gave families a feeling of meaningfulness and the ability to endure difficult situations that could not be changed. For families, God was a positive concept. Helping each other was an essential part of communities with religious beliefs, problems were thought to lead to faith. There was the belief that there was a divine plan for humans and that things would turn out well at some point in the future.

This section makes quite clear that community nursing practice is still developing. Hoskins and Carter (2000) addressed the issue of socio-economic inequality and proposed a new role for community nurses working in the UK. They claimed that nurses could improve community health by identifying and improving those life circumstances that create financial difficulties which in turn have an effect on the person's well-being.

Social capital and its relevance to nursing has recently started to be an area of research interest for nurse researchers as pointed out in the preceding section. It is apparent that nursing research has started to explore issues concerning care provided in the community which is associated with a population aiming to maintain health or manage their condition in their homes and ideally remain active members of the community.

## 2.15 Summary

In this chapter I presented my literature review on patient participation giving a critical analysis of the relevant literature. I attempted to explore the meaning of the concept of participation and present how such a phenomenon is viewed by old persons, nurses and health care professionals such as GPs. This is a selective literature review as already explained (see p 27). Considering that participation in my study is explored in the community setting, I have attempted to provide an overview of the concept as manifested in that specific setting and the related issues. Moreover, discuss and identify the existing gap in the literature.

Participation, as shown in this literature review, is a phenomenon that has increased in importance since the 70s. It has been associated with movements such as consumerism, the democratisation of health care services and community care. Considerable research has been conducted since then from a variety of viewpoints: the health care professionals', the consumers', the patients', for different age groups and they covered many aspects of participation. What still remains to be done is to grasp what is meant by participation in nursing care as it appeared that there is no common understanding of participation among the above groups, not even among themselves.

The literature gives the impression that the meaning of participation can be likened to a complex puzzle where the pieces of which may still be missing or need to be more appropriately fitted together. This study may contribute to that by adding another piece by researching the meaning of participation in nursing care for old persons living in the community. We need to focus on this age group as there are challenges such as ageism that differentiates this age group and we need to focus on the community as it is an area that is still developing for nursing and it has significant differences to that of a hospital.

It was clear from the preceding literature review that participation can contribute to the planning of more effective health care services, and increase the cost

effectiveness of the already existing services. It can also contribute to the improvement of patient satisfaction. There is, though, a grey area regarding the meaning of participation for old persons. Thus, if participation is to be implemented in nursing care, health care professionals have to understand old persons' views and experiences and what these mean to them.



## **CHAPTER 3**

# **THE THEORETICAL FRAMEWORK AND THE RESEARCH PROCESS**

### **3.1 Introduction**

The literature review helped me identify a gap in the existing body of knowledge and state my research question. It became clear that old persons' views and experiences should be investigated if nurses wanted to gain an insight regarding what participation meant for old persons living in the community. Participation as a term is widely used but it was shown that there is no common understanding of it. For an area of nursing that is still developing, community nursing, it would be useful for nurses to gain an insight of what participation means for old persons as they would be able to enhance their developing community practise for a rapidly growing older population. Moreover, Greece lacks research on the area and would be particularly benefited by this study.

Although the literature review has acknowledged that there are factors that may potentially influence participation in nursing care there is still the question of what is meant by participation, as different people may not share exactly the same views and experiences but they may still mean the same thing when they talk about participation. The aim of the study is to gain an understanding of the meaning of participation in nursing care for old persons through the participants' perceptions and experiences.

It is now essential to provide an overview of the research approach adopted in order to answer the research question. In this chapter the theoretical framework will be discussed. This is described as the set of ideas that guided my research practice in order to answer the research question, the set of ideas that form the ontology, epistemology and methodology of my research. These construct the paradigm that I followed in order to reach the aim of this study.

The research process will also be explained and defended. This is divided into a number of stages that are followed in order to perform the study. The process consists of the following: ethical approval, sampling-recruitment-informed consent, selecting the setting, pilot interviews, data collection, data analysis and dissemination of the findings. The account of the process will include practical issues such as sampling and the choice of setting. Confidentiality and ethics as a moral obligation as well as the procedure of obtaining ethics approval and informed consent by the participants are also essential parts of the process. Another issue discussed is rigour, in order to be able to evaluate a research project the reader needs to know how the researcher reached the presented findings (Parahoo, 1997). Another issue discussed will be the decision trail that was used in this study to record the changes in process and later took the form of a reflective diary.

### **3.2 Searching the literature: looking for a method**

The first step in finding out how to perform the study was searching the literature. I started the literature review regarding the research process and the theoretical framework at the end of 2001 by systematically searching relevant databases available in the University of Edinburgh library. Initially, I looked for research published without a time limit, using the keywords 'research paradigms', 'methods', 'methodology', 'sample', 'sampling', 'analysis', 'data collection', 'epistemology' and 'ontology'. The available databases included: CINAHL, Cochrane Library, Medline and ASSIA. All these were used in the beginning on a trial basis. This

search provided an extremely high number of results that was difficult to handle. A quick examination revealed that some results were replicated while others were irrelevant.

As I continued the search I focused on CINAHL and Medline as they concentrate on research concerning nursing practice. The Cumulative Index of Nursing and Allied Health Literature (CINAHL) is the database which provided me with the most interesting results. Medline was used due to its correspondence with the International Nursing Index. Other databases like ASSIA (Applied Social Sciences Index and Abstracts, which aims to cover the needs of health and social sciences) were used on a trial basis but their results either overlapped with results obtained by CINAHL and Medline or were irrelevant. My search was limited to research articles.

In addition, I searched the University of Edinburgh Library Catalogue in order to identify the textbooks that would give me an insight into research design. I used research material within the disciplines of nursing, philosophy, sociology, psychology and education. This research equipped me with the knowledge required to read critically research articles significant for the theory and examples of the application of data collection, analysis, and sampling methods. As explained in the introduction of the second chapter, the limitation of language is also investigated in this literature review (see p ).

### **3.3 The paradigm**

Simmons (1995), in her paper regarding the research process, stated that it is widely accepted in research that the research question guides decision-making regarding methods. Once the research question had been clearly stated, I started to explore the literature in order to identify the most appropriate way to investigate the issue. By reading the literature I came to realize that I needed to decide which ideas would guide my investigation. Denzin and Lincoln (2000) referred to the term 'paradigm' as the principal set of ideas that determine the research process.

Denzin and Lincoln (2000), Webb (2003) and Polit and Tatano Beck (2004) all maintain that paradigms answer basic philosophical questions that characterise research. First, is the question regarding ontology which explains the nature of the inquiry. Then, the question regarding epistemology which is concerned with what the researcher can learn about the world. Finally, the question regarding methodology which explains how the researcher is going to explore the issue under investigation and gain knowledge.

Denzin and Lincoln (2000) also pointed out that paradigms are considered to be abstract mental constructions and a range of their versions can be detected in the literature. Polit and Tatano Beck (2004) referred to two paradigms: the positivist and the naturalistic paradigm. In brief, the positivist paradigm tackles the above issues as follows:

1. Ontology: The world is real and caused by actual reasons.
2. Epistemology: The researcher is neutral and objective and the research findings are unbiased.
3. Methodology: The researcher uses measurable, quantitative, statistical information, the process is deductive (general knowledge can produce specific predictions) and produces generalisable knowledge that is produced with a fixed research design.

On the other hand, the naturalistic paradigm tackles the same issues as follows (Polit and Tatano Beck, 2004):

1. Ontology: Reality is subjective and a mental construction of the individual.
2. Epistemology: The researcher interacts with the research participants and findings are a result of this interaction.
3. Methodology: The researcher uses a qualitative, inductive (specific observations lead to generalisations) process to acquire knowledge. The researcher's interpretations derive from the participants' experiences. The design is flexible.

Broadly speaking qualitative research is usually associated with the naturalistic paradigm and quantitative research is associated with the positivist paradigm (Polit and Tatano Beck, 2004; Denzin and Lincoln, 2000). Furthermore, quantitative studies are primarily concerned with measuring or identifying cause and effect relationships, whereas qualitative studies are concerned with processes, meanings and realities that cannot be measured. It is also possible to combine these two methods (Polit and Tatano Beck, 2004; Parahoo, 1997).

Denzin and Lincoln (1998, p3) argued that

‘qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them’.

Qualitative research gives an account of the participant’s reality (Holloway & Wheeler, 1996). Furthermore, Denzin and Lincoln (1998, p3) pointed out that

‘qualitative research means that the researchers aim to make connections among lived experience, larger social and cultural structures, and the here and now’.

All the characteristics of the inductive approach to research and qualitative research were considered to be advantages that would serve the aim of the study: to investigate the meaning of participation in nursing care for old persons living in the community. Therefore, a qualitative approach was deemed the most appropriate as it is apparent that my research question and aims matched the naturalistic paradigm, as explained above.

### **3.4 Choosing the appropriate research approach: phenomenology**



The next step was to determine the type of qualitative approach that would best serve my research question. It is apparent from the research literature that qualitative research is comprised of a variety of approaches and methods. Therefore, it was vital to identify the one that would best fit this study. Polit and Tatano Beck (2004) pointed out that there is a variety of qualitative research designs that can be grouped according to their focus or their data analysis style, or even according to the discipline in which they were originally developed.

- Ethnography: holistic view of a culture.
- Ethnoscience (cognitive anthropology): mapping of the cognitive world of a culture, a culture's shared meanings, semantic rules.
- Phenomenology: experiences of individuals within their life-world.
- Hermeneutics: interpretation and meanings of individuals' experiences.
- Ethology: behaviour observed over time in natural context.
- Ecologic psychology: behaviour as influenced by the environment.
- Grounded theory: social structural processes within a social setting.
- Ethnomethodology: manner by which shared agreement is achieved in social settings.
- Symbolic interaction: manner by which people make sense of social interactions.
- Discourse analysis: forms and rules of conversation.
- Historical analysis: description and interpretation of historical events.
- Narrative analysis: story telling is the tool in order to grasp how people make sense of certain events they lived.
- Qualitative outcome analysis: identification of strategies and evaluation of their implementation.
- Case studies: in depth investigation of a single entity or a small number of entities.
- Descriptive qualitative studies: presents comprehensive summaries of a phenomenon or of events in everyday language.
- Secondary analysis: analysis of previously collected data' (Polit and Tatano Beck, 2004; p 249).

As I have already stated, my research question guided my search for a suitable research design. In the literature review research papers have claimed that certain factors may influence participation and its perception. It is not clear though how and up to which extent this happens. It can be argued that different people may hold different views and may have lived different experiences but they may still mean the

same thing when they talk about participation. Furthermore, there are a number of overlapping themes found in the literature but not a clear understanding of the meaning of patient participation. Researchers who deal with the issue of participation mention that it is a term that is used with the same meaning as 'patient collaboration', 'patient involvement', 'patient partnership' (Ashworth et al, 1992; Cahill, 1998) and even 'self help', as pointed out in the literature review. Moreover there is not a common understanding not even among the same group of people. In this study I aim to study the meaning of participation and see what is the essence of participation for old persons living in the community.

When I searched the literature to see which methodological approach would be most appropriate and compared the possibilities as listed above with my research question, as explained in the previous paragraph it is apparent that grounded theory, ethnography and phenomenology are the ones closer to my purpose. In brief, grounded theory aims to develop explanatory theories on essential social processes (Glaser and Strauss, 1967); ethnography aims to elucidate and interpret a particular culture or social group (O'Byrne, 2007) and comprehend complexity by methodically studying significant relations (Huby et al, 2007); phenomenology, studies individuals' experiences and perceptions in their environment (Anderson, 1991; Holloway & Wheeler, 1996; Morse & Field, 1996) and focuses on the investigation of the meaning of phenomena. Thus, phenomenology is the appropriate approach to perform the study. Moreover, Annells (1999, p6), in her paper regarding the usefulness of phenomenology, proposed four categories of purposes for phenomenological research, among them the

'pathic understanding-concerning human life, inclusive of aspects like feelings/emotions, interactions, meanings, and responses; useful for empathic nursing action'.

The word 'pathic' was earlier used by van Manen, and is derived from the Greek word *pathos*. Annells used it to describe a situation in which a nurse manages to grasp the 'heart' of somebody's existence and support that person when suffering or in need.

According to Omery et al (1995, p141), phenomenology

‘holds that reality consists of the meanings in a person’s lived experience. Humans know the world only as they experience it, only as they through their consciousness act upon it and interact with it’

and concludes that ‘it is in lived experience, then, that knowledge is grounded’.

Morse & Field (1996) suggested that the goal of phenomenology is to describe the experience of the phenomenon under study and not to generate theories or models, nor to develop general explanation.

The purpose of this study is to gain an understanding of how old persons perceive and experience the phenomenon of participation in nursing care and hence to gain an understanding of the meaning of participation as they perceive it. As a result, because phenomenology accepts experience as it exists in the consciousness of the individual (Morse and Field, 1996) it will give an answer to the research question and help health professionals to gain useful insights into the issue under investigation.

### **3.5 Choosing the appropriate phenomenological movement to perform the study**

By searching the literature I came across a variety of phenomenological approaches that should be considered in view of my research question so that I could make a decision on which approach of phenomenology would be most appropriate for my research question. Spiegelberg (1960), one of the most established figures in phenomenology, pointed out that there is great difficulty in stating what phenomenology is. Although it is a movement that developed its own identity from an early stage, the fact that it keeps re-interpreting itself poses a challenge to the researchers that are willing to use it (Spiegelberg, 1960; Giorgi, 2000). Furthermore, due to the complexity of the meanings, researchers have to be careful with the

philosophical underpinnings of their studies. Here, I have to mention that the issue of terminology is also an issue that needs attention (see p 106-112) and original terms will be used to avoid misunderstandings and pre-empt criticism for not staying true to the original meaning of the term.

A historical overview of phenomenology will give a useful insight in the existing trends in the area. It is considered an essential part of this chapter as the choice of the appropriate phenomenological approach was necessary in order to perform the study. It is crystal clear in the literature on phenomenology that there is still a dynamic of constant change and re-invention as there is still much discussion regarding its implementation (Crotty, 1998; Giorgi, 2000). Caeli (2000) presented this modern discussion as a result of the existence of European or traditional phenomenology and American or Continental phenomenology. The former presented a common characteristic in its forms as a search for 'the objective reality of the things themselves' while the second is predominantly concerned with the 'exploration and description of everyday experience itself' (Caeli, 2000; p 369).

As far as the origins of phenomenology are concerned, Cohen (1987) argued that phenomenology had a preparatory phase that started with Franz Brentano (1838-1917) and Carl Stumpf (1848-1936). Brentano's ideas of people being aware of their psychic phenomena and intentionality were considerably important. Stumpf was Brentano's student and founded the movement of experimental phenomenology, which was based on the analysis of empirical data.

Cohen (1987) characterised the period that followed as the German phase, dominated by Edmund Husserl (1859-1938) and later by Martin Heidegger (1889-1976). Although Heidegger was initially Husserl's assistant for a period of time, his approach developed significant differences in comparison to Husserl's. Heidegger's ideas influenced and inspired the French phase that followed, as in Germany Nazism ended phenomenological inquiries.



Historically, Husserl was thought to be the one who established modern phenomenology. According to his approach, phenomena should be studied as they appear through consciousness, and experience was considered as the ultimate ground and meaning of knowledge (Cohen, 1987; Koch, 1995, Walters, 1995). The Husserlian phenomenological approach (Cohen, 1987; p33) proposed the following two concepts as central in the movement: intersubjectivity, which was defined as the state where 'a plurality of subjectivities makes up a community sharing a common world' and life world which was defined as 'the world of lived experience'. Another concept central to Husserlian phenomenology is reduction (see p 113). Cohen (1987) argued that reduction was performed in two steps: bracketing and epoché.

Taylor (1995) defined bracketing as a means of acquiring the 'anatomy' of consciousness which is a result of suspending consciousness in order to isolate phenomena. By using bracketing the things themselves can be grasped before any preconception of an external reality (Crotty, 1998). Epoché, on the other hand, is the use of bracketing of the researchers' own consciousness. Bracketing has proved to be one of the most challenging concepts in phenomenology. I will discuss it in detail in the next section.

In the same vein, Sadala and Adorno (2002) suggested that the phenomenological approach developed by Husserl gave researchers the ability to keep only the essence of the investigated phenomenon. According to the Husserlian approach, phenomena should be studied as they appear through consciousness, and experience was considered as the ultimate ground and meaning of knowledge (Koch, 1995). According to Hallett (1995), the value of phenomenology lies in the fact that it focuses on the participants' perceptions and gives the researcher the opportunity to gain an in-depth account of the researched phenomena. This is congruent with the notion of intersubjectivity, and can be achieved by bracketing and by researching the world of lived experience which are elements of Husserl's phenomenological approach.



Heideggerian phenomenology is also described as 'existential phenomenology' and as Gadamer later developed it, 'philosophical hermeneutics'. Heidegger supported the idea that human beings always come to a situation with a story or pre-understanding, which is something that we cannot bracket or eliminate (Heidegger, 1960). He also expressed the opinion that people are self-interpreting beings. According to Heidegger, even the researcher brings their pre-understandings to the text (Koch, 1995). Heidegger introduced the notion of historicity of understanding and the hermeneutic circle (Cohen, 1987; Koch, 1995; Holmes, 1996). Koch (1996, p 177) suggested that

'the application of bracketing and the hermeneutic circle are mutually exclusive'.

Heidegger's Nazi involvement is an issue that has preoccupied researchers, philosophers and historians (Cohen, 1987; Holmes, 1996) since the fall of the Nazi regime. The question that has preoccupied everyone is whether his Nazism was related to his philosophy or should only be seen as a personal weakness. What is however considered a fact is that Heidegger's involvement in the Nazi party resulted in a decreased concern in phenomenology and therefore fewer publications (Cohen, 1987).

According to Holmes (1996), even apologists such as Steiner wrote that there are significant similarities between Nazism and ideas expressed in 'Being and Time' (Heidegger, 1960), for example, the ideas of the inseparable hand and body or the labourer and his tools that can be seen clearly when presented with no preconceptions or pretension. Holmes (1996) strongly argued that Heidegger was a Nazi who could be characterised as extreme in his views even by comparison to the Nazi party of the time. The fact that he never argued against his wife's publicised views regarding racial inequality or the use of sick and pregnant women for heavy manual work is presented as a further example of his Nazi ideology.

Even after the fall of Nazism in Germany, Heidegger was attracted to fascist writers and never condemned Nazism and its consequences for the world (Holmes, 1996).

These are issues that have to be taken seriously into consideration when a researcher chooses an approach but this is not often cited in nursing papers even in cases such as Koch's (1995) that discusses the influence of Heidegger on nursing research. Holmes (1996) suggested that Nazism and the philosophical movements that are related to it are not congruent with nursing and that could result in the rejection of Heideggerian philosophy when conducting nursing research. It is obvious from the literature that there is a debate whether Heideggerian phenomenology can be used without being associated with Nazism, a fact that causes ethical implications for those studies that use it.

As soon as the Nazi regime took over in Germany, phenomenology moved to France. The main representatives of the French phase were Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961) as mentioned by Cohen (1987). Although Marcel and Sartre used phenomenology, they never considered themselves phenomenologists (Cohen, 1987). Merleau-Ponty was the one that first published a work with the term 'phenomenology' in the title and was eager to show that a phenomenological approach could offer valuable insights (Cohen, 1987).

At the same time, psychiatrists and psychologists started to use phenomenology to study therapeutic techniques (Cohen, 1987) and scholars became interested in exploring and inventing other phenomenological approaches. Valle and King (1978) suggested that phenomenological research in psychology aims to reveal the meaning of the phenomenon that the participants experience (live) and how it is experienced in everyday life. In the literature there is an interest of nurse researchers in phenomenology as performed in psychology (Rieman, 1998).

In addition, Gadamer (1990) explored hermeneutics but he did not propose a method of analysis. This was done by van Manen (1990). Spence (2001) summarised philosophical hermeneutics in the following statement:

'philosophical hermeneutics takes the view that understanding is both a process and a mode of being. Traditions and understandings

are thereby inherited through language and the non-conscious process of socialization. However, neither traditions nor understandings are unidirectional phenomena but dialectical and dialogic' (Spence, 2001; p 625).

In hermeneutics the issue of language is an important element of the research process as Taylor (1995) discussed. Gadamer's idea was that all understandings are linguistic. Annells (1996) pointed out that the concept 'hermeneutics' comes from the Greek word 'hermeneia' which means 'bringing to understanding particulars where the process involves language' (Annells, 1996, p 706). According to Taylor (1995), hermeneutics were seen as the method through which an effective historical consciousness could lead to the description and identification of truth and prejudice.

In this particular study I aimed to describe a phenomenon through the participants' perceptions and experiences so that an understanding of the meaning of the phenomenon for old persons living in the community in Greece could be achieved (also see p 5-6). This is congruent with the notions of intersubjectivity, and can be achieved by bracketing and by researching the world of lived experience which are elements of Husserl's phenomenological approach as presented in the above section. As mentioned earlier, by using bracketing the things themselves can be grasped before any preconception of an external reality. Novice researchers such as myself do not just read the theoretical elements of phenomenology and then proceed to its unmistakable application. We tend to read other papers and try to learn from these and prepare ourselves to avoid mistakes, if possible. This reading is art of my background and needs to be acknowledged as it played a significant role in performing the study. Without the acknowledgement of my reading and the related practical issues I encountered, my decisions on methodological issues would not be adequately explained.

### **3.6 The quality of qualitative research**

### **3.6.1 Rigour in qualitative studies**

One of the main concerns was the issue of evaluation for this study. It is obvious in the literature that qualitative researchers are eager to move from the traditional positivistic view of rigour and develop other views that are more suitable to the paradigm they are committed to. Webb (2003), in her paper regarding guidelines on reporting qualitative studies, argued that rigour is an essential element of a qualitative research report and it should be appropriate for that kind of research. In the same vein, Denzin and Lincoln (1998) argued that the research paradigm will determine the evaluation criteria. It is evident in the literature that qualitative researchers are eager to move away from the traditional positivistic view of rigour and develop other views that are more suitable to the paradigm they are committed to.

Tobin and Begley (2004) argued that considering that qualitative and quantitative research have different ideological underpinnings it could be problematic to use the same evaluation criteria. Furthermore, language is the means through which philosophical constructions are expressed and this differs across philosophical approaches. It is therefore questionable whether terminology can be common across research paradigms. Denzin and Lincoln (1998) echoed this, indicating that rigour needs to be relevant to the research paradigm that the researcher follows.

The option of not having any predetermined criteria and that instead every researcher should develop their own criteria fitting their study has also been proposed (Annells, 1999). Koch (1996) argued that researchers should decide for themselves how rigour is addressed in their study, not only by selecting the appropriate criteria from the literature but also conceiving new ones to fit their study whenever the literature cannot address all of the issues. As stated in her paper, the researcher needs to decide which are the most suitable criteria for their study, but the readers will eventually evaluate the study with their own criteria.



In any case a researcher's main concern should be the provision of evidence to the reader that the study is trustworthy. The most suitable tool for this is a detailed and honest description of the theoretical framework and the research process (Annells, 1999; Bowling, 2000; Holliday, 2002). The main aim of the investigator should be to prevent bias and error in the research process especially in sampling, data collection and analysis (Bowling, 2000).

Brink (1989) summarised the research errors that can occur throughout the research process. It could be as small as a typing error and in any stage of the research process. It could be from the statement of the research question to the sampling method, or while selecting data (problematic researcher-participant relationship, environment that is not suitable to perform interviews, problems with equipment), or even with the analysis.

Moreover, detailed records should be kept regarding the research process. A number of researchers (Koch, 1996; Bowling, 2000) advise a reflexive diary or trail of decisions (or audit trail), detailing the decisions, difficulties, feelings and personal views of the researcher as a helpful tool in enhancing rigour, especially in Husserlian phenomenological research due to the use of bracketing.

After having decided on my research design I started to keep a diary. This proved very significant, especially after having decided my research approach. It proved that this decision trail or, as others call it, audit trail, is an essential element of rigour. One of the essential elements of this study was epoché. In order to be able to achieve this, I decided that I could use a diary to keep track of my own thoughts, feelings and discussions during the research process. I considered this a way of continuing epoché.

Although I started using this type of diary for reasons of rigour, I gradually started using it also as a reflexive journal and as a diary that I could use to keep up with my appointments. Due to the fact that I chose to use Husserlian phenomenology I thought that it could be a useful tool to practise bracketing. I found myself acquiring



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the habit of documenting feelings, thoughts and ideas that were all in a continuum. This was very significant as I could keep track of the development of my own thinking as a researcher.

Moustakas (1995) proposed that before each interview the researcher should practise epoché. This suggestion, which I found feasible and in congruence with my methods, was practised in all cases. These entries in the diary were an essential part of the process. I must say that I did not distinguish these entries from the thoughts and decisions that were relevant to the process. The reason was that my knowledge of the issue under study influenced my research process and design and vice versa. Therefore, I felt the need to document everything in parallel, while performing epoché.

Sometimes it was difficult to keep writing my diary. As I went on with my research and felt more certain of myself I was not even sure that I actually needed it. My entries became smaller and sometimes I felt that I was repeating myself. Soon I realized that the diary was however very important as this was the only way that I could keep track of my thinking. As time passed, I started recording, writing in notebooks and keeping notes at the side of my papers and transcripts. Fortunately I realized that this was not the best option and I began writing my diary (or audit trail or decision trail as other people call it) in small notebooks that I carried everywhere with me for that purpose.

In this chapter I describe how I acquired and analysed my data and having as a source this diary I present my journey along the theoretical underpinnings of the study. In addition, I provide information to the reader on how I performed epoché and illustrations of how I used it to focus on the participants' views and experiences to reach my aim.

Emden et al (2001) performed a study consisting of a sample of postdoctoral nurses and midwives from different countries in order to determine what they regarded as a good qualitative research report. The results of this study show that their comments

concentrated on the research process, writing, outcome and excellence. As far as the process was concerned, they felt that 'attention to detail with honesty and trustworthiness' (Emden et al, 2001, p 210) was essential, as far as the writing was concerned, the report should be

'written with impact, effect, meaning and believability' and the outcome should 'relate usefully to practice and other/ongoing research'(Emden et al, 2001, p 210).

Finally, as far as excellence was concerned, participants said that a report should 'show that quality is important, consensual and achievable' (Emden et al, 2001, p 210).

Tobin and Begley (2004) attempted to tackle the issue of rigour in qualitative research. Their article presented the divide between qualitative and quantitative research that is now developed. It is stated that the criteria of validity, reliability and generalisability are quantitative criteria that were initially used in qualitative research but it is now evident that qualitative researchers are attempting to find their own criteria that would be more suitable for their research. They warned qualitative researchers, though, that the rejection of criteria can lead to the rejection of qualitative research as a scientific process.

According to Annells (1999), the classic criteria of quantitative research, ie validity, reliability and generalisability, are not useful in phenomenological research as it is an approach that is not characterised by strict processes. Instead, Annells (1999) presented a set of criteria that are developed in parallel of the classic criteria and could be used in qualitative and if chosen in phenomenological research. They are:

- **Credibility:** this is concerned with if and how the information given by the participants is presented by the researcher.
- **Transferability:** this replaces the concept of generalisability in qualitative research. In qualitative research findings are not generalisable to the population but they can be transferred across cases.
- **Dependability:** this refers to how clearly the research process is explained,

regarding both its theoretical framework and its implementation.

- **Confirmability:** this is concerned with whether the findings derive from the data collected and represent the information gathered by the participants.

Furthermore, she argued that the following criteria are fit to be used specifically in phenomenological research:

- **Understandable and appreciable:** research reports should be easy to read and pleasant to the reader. Reports that are difficult to understand by the majority can be questioned for their significance as the findings should benefit the majority of nurses and not only experts.
- **Understandable process of inquiry:** The researcher should provide all the information needed to the readers so that they can understand how the different decisions regarding the research process were made. A 'decision trail' should be offered.
- **Useful:** Researchers need to do studies that benefit nursing practice and those who receive it. This needs to be made explicit in order to prove to the readers that the project was worthwhile.
- **Appropriate inquiry approach:** In phenomenological research this is very significant as there is a variety of phenomenological approaches that the investigator needs to take into consideration and clearly state which one is applied in the study.

Other researchers such as Rose et al (1995) provided a brief examination of rigour in phenomenological research and proposed the following criteria:

- **Credibility:** In phenomenology, credibility is gained by bracketing. The process of achieving bracketing needs to be explicit to the reader especially because it is debated whether bracketing is achievable.
- **Methodological consistency:** the use of the appropriate design and phenomenological approach needs to be clear.
- **Congruence of phenomenology and nursing:** both share a humanistic view of the world.

- Applicability of phenomenology: a researcher needs to ask whether the findings generated by phenomenological research are applicable to nursing practice.

It is apparent that rigour is something that cannot be prescribed in qualitative research for all its approaches hence there is not a common set of criteria in the literature. In this study, using Husserlian phenomenology means performing epoché throughout the data collection and analysis, consequently, keep the process uncontaminated by my views and perception. In addition, using Colaizzi's method of data analysis means that my analysis was validated by the participants (see p. 163). In addition, according to qualitative standards I had to describe clearly how I obtained my data and how I analysed them. At the end though, it is up to the reader to decide whether this is a quality study as Rolfe (2006) also pointed out.

### **3.6.2 Rigour and translation in research**

Twinn (1997) researched the consequences of translation for the validity and reliability of qualitative nursing research, although, as I discussed earlier, it is debated whether the terms validity and reliability are appropriate to be used in qualitative research. Twinn's (1997) study involved the translation and transcription of interviews by two independent translators into English and their transcription by a third person into Chinese. Then the data were analysed and themes were developed.

Even though the main themes that emerged in all three cases were similar there were some issues of concern for the researcher. First, the story was interpreted in a different way in translations and second, there were words that could not be translated as there was not a direct correspondence in other languages. In addition, there were differences between the two translations into English. Another issue she noted was that material that was not relevant to the matter under investigation in the interviews was not easily detected in the translated text.



In addition, other researchers such as Clarke (1992) observed that there are differences in languages that have to be carefully considered. She gave a simple example: in English 'you' has a single as well as a plural meaning while in French there are two different words. This is the same case in Greek.

The above were major issues of consideration for me as my research would be carried out in Greek and I would then have to translate into English. The above study helped me realise that the analysis of my data would be more appropriately done in Greek and I could then translate my findings. Further reading, especially from the area of linguistics, helped me realise that I would lose valuable material if I analysed my data after translating it. In addition, I decided to translate the material that I would include in the presentation of my findings myself, as I wanted to make sure that translation was consistent throughout the study.

Moreover, I thought that I was the most suitable person to translate my findings, as I would perform the interviews, transcribe them, and perform the analysis. Then I would have a professional translator check my translation in order to make sure that I had presented the best possible translation and avoided misunderstandings. As Twinn (1997) pointed out, phenomenological studies aim to illuminate the essence of phenomena, therefore the participants' views need to be clearly understood by both the researcher and the reader.

Koskinen (2004), in her paper about trends in translation, stated that translation is done across cultures and not languages. Languages are developed within a cultural environment and words represent concepts that are developed and understood within a context that might not be commonly understood by all cultures.

Koskinen's argument was supported by other researchers like Panayiotou (2004). Panayiotou (2004) performed a study that investigated the existence of similarities or differences in the responses of bilingual people in English and Greek. She argued that

‘emotions are language dependent, as the raw or bodily experience of an emotion must be filtered through a cultural meaning-making system’ (Panayiotou, 2004, p 125).

In order to investigate her argument she performed a study using bilingual participants who were presented with a scenario in both English and Greek. The results showed that ‘to the extent that language use implies a certain cultural context, certain experiences can occur only within the context of a specific language’.

In addition, it was mentioned by the participants that some words when translated from one language to another could not fully express the meaning of the experience or even be translated. This is particularly significant in a phenomenological study like mine, which performed a study in one language but communicates the findings regarding the meaning of a phenomenon in another. I thought that the quotations used to support my analysis would be the most problematic. This is one more reason that I decided to translate by myself as I performed the study, but again using a professional translator to verify my translations.

It became clear in this section that rigour needs considerable attention not only on behalf of the researcher but also the readers. I had to decide for myself as indicated by the literature which criteria I would adopt. In addition, I had to pay attention to the issue of translation as phenomenological studies are primarily concerned with the meaning of phenomena and these need to be clearly communicated to the readers. The issue of sampling and its importance in qualitative research was also discussed under the light of the new approach of transferability that is proposed instead of generalisability.

### **3.7 The challenge of using phenomenology for nursing research**

Deciding that I would use the phenomenological approach for my research was not an easy decision to make. The literature review made me aware of a heated discussion regarding its application. As explained above, phenomenology is

comprised of a variety of approaches (Jasper, 1994; Tatano, 1994; Walters 1995; Polit & Tatano Beck, 2004). Researchers like Corben (1999) and Barkway (2001) explored critically its implementation within nursing as it is a philosophical approach that was later adopted by health care professionals like psychologists and nurses and further suggested to be a method of scientific inquiry (Giorgi, 2000). There are still arguments concerning the use of phenomenology in different disciplines. For example, Naudin et al (1999) argued that the use of phenomenology in psychiatry is the case of a philosophy that can be applied in a scientific field. He thought that Husserlian phenomenology gave the foundation of a critical epistemology and a rigorous way in to direct experience.

In terms of using the Husserlian phenomenological approach there is much critique in the literature. Paley (1997) argued that nurse researchers tend to claim that they conduct phenomenological studies following the Husserlian approach but their research practice does not justify their claim. Paley (1997, 2005) criticised nurse researchers as having misunderstood essential concepts in phenomenology and Husserl's philosophical approach thus they do not conduct research according to the Husserlian perspective although they claim they do. First of all, because they did not use reduction the way Husserl had described it. Secondly, because the aim of their studies is not congruent with Husserl's ideas. Husserl (1931) aims to return to the things themselves with the use of phenomenological reduction. Nurse researchers research phenomena such as emotions through other people's lived experiences and by putting aside their own views and preconceptions. According to Paley (1997) Husserl's approach in understanding the external world is through the researcher's own consciousness. Husserl would not turn to others in order to go 'back to the things themselves'. Furthermore, Paley (1997) argued that small and unrepresentative samples seem to be the case in nursing studies which makes their significance questionable.

In the same vein, Crotty (1996) argued that nurses claiming that they use phenomenology do not actually perform phenomenological studies but they rather perform another type of research that is developed from North American researchers.

He argued further that nurse researchers should be careful when they claim that they follow the Husserlian or Heideggerian approach if they use this new North American approach to phenomenology which focuses on researching issues through the experiences of the others in contrast to the so called European phenomenology, which is concerned with our own consciousness and use it to grasp new meanings or rediscover meanings.

On the other hand, Dermot (2000) argued that although Husserl was preoccupied with acts of cognition rather than the emotions of human actions, he never devalued these areas of interest. Thus, Husserl never suggested that phenomenology cannot be used to research emotions and human actions. The fact that it was used in certain areas of interest has shown the areas of interest that the investigator was pre-occupied with and not the limitations of the approach.

Barkway (2001) in her critique on Crotty's arguments (1996), regarding the use of phenomenology by nurses, referred to his background. She presented him as an authoritative figure with integrity who dared to defend his opinion and accept the challenge of opposition. An example was given that was quite characteristic, as a priest he questioned the Pope and his suggestion of the ban of the contraception use. Although his opposition attracted attention and led to his resignation from the priesthood and him moving away from his country, he remained steady to his beliefs and defended his opinion. This stance, had shown that Crotty is a person of strong character and also a wandering mind that critically views the world and can accept the challenge of expressing an argument as well as defending it. Thus, Barkway presented Crotty's critique as valuable due to the personality of the person that expressed it. Although Barkway's claim (2001) regarding his personality made sense it did not though reinforce Crotty's critique regarding the use of phenomenology by nurse researchers.

On the other hand, Giorgi (2000) replied to Crotty's critique and he suggested that he had biased views about phenomenology and, when compared with Husserl's original writings, seem to be based on misinterpretations. Furthermore, Giorgi (2000) argued



that Crotty did not make a distinction between scientific and philosophical phenomenology. He concluded that if researchers practised what Husserl suggested, they would be practising philosophy and not scientific inquiry. Therefore, Crotty's arguments regarding phenomenology cannot apply in the case of research studies.

In addition, Lawler (1998) criticised Crotty for focusing his critique in North American studies. Lawler (1998) argued that not all aspects of the issue have been investigated, thus the argument presented cannot be considered representative of the whole nursing phenomenological research that is performed. Lawler (1998) also made the claim that phenomenology is influenced by the different cultures that it is developed within, thus it would be reasonable to say that they are also influenced by the different disciplines that they are developed in.

It is interesting to study how modern researchers view Husserl's writings as there is no doubt that phenomenology has moved on and Husserl's approach might be implemented with variations that does not necessarily make them something different than phenomenology and than what Husserl suggested. In addition, it is apparent that Husserl as the founder of phenomenology and the one who suggested and discovered the use of significant devices such as bracketing needs to be cited. There is the need for researchers to be able to demonstrate that they know what Husserl recommended and be able to demonstrate what and how they did it as in research rigour is essential.

There is though the question of how significant it is to nurses to prove that they indeed practice phenomenology exactly as Husserl intended. It is undoubtedly significant to practice quality studies that will contribute to adding in the already existing body of knowledge in an ethical and rigorous way aiming to improve nursing practice. Thus there is the need of performing rigorous research. In order to achieve that nurse researchers do need to refer back to Husserl, even if their approach moves phenomenology forward, as this will prove not only their knowledge and ability to use their research method but because this constitutes their philosophical background. There is also the need to clarify details of the methods so that readers



can judge whether the researchers know what they are doing and that their data are significant and rigorous.

Omery et al (1995) claimed that for Husserl, philosophy and science are connected as he considered that science needed rigour and could be achieved by returning to the things themselves, one of the aims of phenomenology. Giorgi (2000a, 2000b) on the other hand, argued that what Husserl practised was philosophy and not science and that there was the need of developing a scientific method so that it can be used effectively in research. Although, these two views cannot be considered as opposite it is an example of how debates can arise regarding the use of phenomenology when they are not viewed in context.

In the same vein, Giorgi (2000b,) suggested that phenomenological philosophy is a foundation for scientific work but not a model for scientific practice. He stated further that:

‘the employment of the scientific phenomenological method involves description, reduction and the search for higher level invariant meanings, or essential structures that are typical for contexts, on the part of the researcher. Moreover, replicability is possible either by having another researcher re-perform the analyses already done, or having other researchers in other places obtain new descriptions of the same phenomenon and apply the same method, enabling them, in principle, to come up with the same findings’ (Giorgi, 2000b, p11).

Furthermore, in an early stage I came to realise that the use of phenomenology is nonetheless challenging as it is based on philosophical grounds and it involves terminology that needs to be clearly understood. Corben (1999) pointed out that the terms that are associated with the phenomenology can cause misunderstandings as the original texts were written in German and the terminology is complex. For example one of the terms used in Husserl’s writings was the term ‘object’, which had a broader meaning than the standard use and included abstract things like concepts. Therefore, while using bracketing or reduction or epoché, the researcher should make sure that terminology is understood correctly. The use of the source to explain each

term is important to avoid misunderstandings. In addition, researchers should be able to demonstrate that they are aware of the theoretical elements of their approach and that they are able to use it correctly. Although in a PhD theses terminology should be avoided I suggest that in this case that there is so much discussion regarding the phenomenological terminology, terms should be used as an exception (and be explained by going back to the source) so that the readers can judge for themselves whether the author has understood and used phenomenology rigorously.

Another point that is raised is the use of secondary and tertiary sources which means that the researcher relies on the interpretation of others. The literature stresses that researchers wishing to use phenomenology should avoid using secondary and tertiary sources as guideposts, but refer to the original scripts (Cohen, 1987). On the other hand it could be argued that nurse researchers need to refer to the modern nurse researchers as they need to know the new developments in nursing research. Phenomenology proved to be an approach that keeps re-inventing itself (see p 94) and nurses need to know the new developments and be able to defend their own choices and be able to perform rigorous research. In such cases these sources are not secondary and tertiary sources.

According to Hallett (1995), the value of phenomenology lies in the fact that it focuses on the participants' perceptions and gives the researchers the opportunity to gain an in-depth account of the researched phenomena. As Crotty (1998) pointed out, phenomenology in general suggests that the researcher should leave aside any understandings and preconceptions that already exist and have a 'fresh look' at things. This can result in new meanings or at least an authentication and enhancement of the already existing meanings.

Jasper (1994) commented that the focus of phenomenology, which is the clients' experiences, can be used to plan future care because the clients' needs can be identified, and the results of such research can contribute to the provision and justification of high quality care. Therefore, although phenomenology poses

considerable challenges, it worths the effort as not only does it serve the aim of the study but also offers considerable advantages to nursing practice in general.

### **3.8 The challenge of bracketing**

Phenomenology, as presented by Husserl, is a philosophical movement and not a research method (Giorgi, 2000a; 2000b), as explained. As a result, I became interested in bracketing not only as presented by Husserl but also in terms of the way it has been performed in recent research studies and presented by well established researchers. Although the terms reduction, bracketing and epoché are used interchangeably in the literature, there are conceptual differences that needed to be explored and clarified before starting the implementation of the study.

Sadala and Adorno (2002) argued that what Husserl created gives the certainty to researchers that they keep only the essence of phenomena under investigation. Nevertheless, according to Corben (1999), using bracketing as a research method is misusing its original meaning. In the same vein, Paley (1997) suggested that there is a misunderstanding in the nursing field of key concepts like 'bracketing' and epoché, which are not research techniques but rather philosophical ones. Furthermore, Paley (1997) argued that nurse researchers do not bracket in the Husserlian sense.

In his response, Beech (1999) argued that nurses do bracket in the way psychological phenomenology proposes. Valle and King (1978) reasoned that phenomenological psychology aims to answer which phenomena show themselves and how they do so. They also pointed out that the 'constant unchanging structure' (Valle and King, 1978, p 15) of the phenomenon becomes known only when the researcher sees the varied reflections and appearances of the phenomenon repeated.

Yegdich (2000) explained that there is a distinction among philosophy and psychology as psychology actually is concerned with actual experience while phenomenology is concerned with 'ideal' essences identical to a pure type of

meaning. According to Yegdich (2000), the nurses that use phenomenology use bracketing in the natural attitude because they aim to refer accurately to the participants' experiences and not to phenomena or the things themselves.

The debate that is developed in the literature made me more aware of the need for understanding the related terms. In order to be able to understand bracketing in the Husserlian sense we need to understand its philosophical origins. Walters (1995), in her comparative review of Husserl's and Heidegger's phenomenological approaches, argued that Husserl was influenced by the Cartesian tradition, which is accepted by other researchers such as Koch (1995). Therefore, the relationship of man with the world is of him being a subject that knows objects. Furthermore, Husserl was considered to be aiming at an extension of the Cartesian rationalism (Hallett, 1995). The concept of bracketing was formed within this philosophical approach.

Moustakas (1995) and Walters (1995) described the phenomenological reduction as the reduction of a phenomenon in its components by putting aside any existing preconceptions. Walters (1995) claimed that Husserl as a mathematician used the term bracketing, which as Cohen (1987) pointed out is a mathematic metaphor, to describe the phenomenological reduction.

According to Moustakas (1995, p 97), who studied phenomenology in depth, bracketing is a stage of reduction, which has the following stages:

'Bracketing, in which the focus of the research is placed in brackets, everything else is set aside so that the entire research process is rooted solely on the topic and question; horizonalizing, every statement initially is treated as having equal value. Later, statements irrelevant to the topic and question as well as those that are repetitive or overlapping are deleted, leaving only the Horizons (the textural meanings and invariant constituents of the phenomenon); Clustering the Horizons Into Themes; and Organizing the Horizons and Themes Into a Coherent Textural Description of the phenomenon'.

This description is congruent with Husserl's suggestions in 'The Crisis of European Sciences and Transcendental Phenomenology' (Husserl, 1970). According to Naudin



et al (1999), there are two phases in the meaning of epoché for Husserl. The early phase is outlined in the 'Logical Investigations' in which Husserl suggested that 'preconceived theories and presuppositions' should be left aside in order to 'get back to the things themselves' and thus view phenomena as they appear to the observer. The later phase is expressed in 'Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy, First Book' and it is here that the change of epoché to transcendental epoché is suggested. Therefore, the natural attitude is suspended and the world is viewed as 'constituted by consciousnesses'. Not all researchers make the distinction mentioned above.

The term epoché is also found in the literature as another term for the same technique (Walters, 1995; Corben, 1999). Moustakas (1995) explained that the term 'epoché' derives from a Greek word which means 'to stay away from' or 'abstain'. According to Moustakas (1995, p85), epoché is the process by which the researcher sets aside 'prejudgements, biases, and preconceived ideas about things'. Thus, what remains is bracketed.

Overgård (2003) suggested that Husserl described a procedure that puts aside (brackets) accumulated past knowledge while doing phenomenological research. Husserl named this procedure 'epoché'. The epoché does not turn the researcher into a sophist or sceptic but simply instructs not to use certain knowledge while engaged in an investigation (Koch, 1995; Giorgi, 2000; Overgård, 2003).

Husserl (1970, p 148) himself referred to the transcendental epoché as

'a total change of the natural attitude, such that we no longer live, as therefore, as human beings within natural existence, constantly affecting the validity of the pre-given world; rather, we must constantly deny ourselves this'.

Giorgi (2000) viewed what Husserl proposed as a way of setting aside any preconceived notions without being a sceptic or a sophist. The 'noema' (essence) of the phenomenon can thus be grasped (Overgård, 2003). It can therefore be stated

that phenomena are grasped in their essence when researchers perform bracketing (Ashworth, 1999; Omery et al, 1995; Koch, 1995).

In practice, for me, the above discussion was summarised in the following: I should set aside anything I had in mind regarding the issue under investigation so that I could bracket the participants' views and experiences and achieve reduction. I knew what I wanted to do but the crucial question was how would I achieve it. In the literature I came across papers where the authors argued that bracketing is not feasible.

Corben (1999) questioned whether epoché is achievable as she argued that the unconscious cannot be bracketed and can influence the study. Cutcliffe (2003) also argued that there is only a small part of people's consciousness that people are aware of and since Freud it has been debated that a large part of our mental activity is not conscious. Therefore, it could be argued that we are not capable of performing epoché.

However, other researchers like Colaizzi (1978) claimed that the scientist can live his everyday life as an ordinary person and still deny his everyday life experiences when practising science. This is not presented by Colaizzi as an extraordinary quality but rather as a usual practice as there are many occasions when a person can have multiple roles which results in distancing their theories from their experiences according to the occasion. In addition, according to Colaizzi (1978, p52), 'objectivity is fidelity to phenomena'.

In the same vein, Moustakas (1995) pointed out that the researcher as a conscious person remains present even during the epoché and this is how and why it is possible to conduct the epoché. It is, though, admitted that it is difficult to perform epoché perfectly and not everything can be bracketed. Epoché, however, gives the opportunity to researchers to have a fuller and closer look at phenomena. Tatano Beck (1994) argued that it is the acknowledgement of all preconceived knowledge

that makes bracketing possible. Thus, time and effort need to be spent in order to achieve this difficult task.

Although there are criticisms as to whether epoché is possible (due to the fact that the unconscious is something that people are not aware of), as has been mentioned we can still be aware of the knowledge that we have accumulated and our motives that relate to the research and the criteria of validity. Therefore, phenomenological reduction might be difficult but yet achievable.

In addition, I came across papers written by other researchers such as Lowes and Prowse (2001) who argued that in nursing research, although researchers claim to practise epoché, they usually do not state how or why this is done. Furthermore, Crotty criticised nurses for applying phenomenology and more specifically bracketing (Crotty, 1996) in a naïve way. Crotty definitely has to be taken into consideration, as Barkway (2001) argued, as his critique could be used in nursing practice.

There is also discussion in the literature regarding what should be bracketed and how. Koch (1995) argued that the initial step in Husserlian phenomenology is the exclusion of all preconceived notions and later on noted that Husserl added the ultimate level of transcendental phenomenology, bracketing the external world as well as the individual consciousness.

In addition, Ashworth (1999) suggested that there are two main categories of preconceived notions that should be bracketed: anything that is related to already accumulated knowledge and the criteria of validity that arise outside the life-world. According to Ashworth (1999) bracketing also has to follow the psychological-phenomenological reduction, as suggested by Husserl, which means that the researcher holds no position on the correctness or falsity of what the participant claims and phenomena are to be understood according to their own systems of meaning.

I have to admit that what Koch and Ashworth suggested was too general for me in the beginning. At a later point I found a paper by Cutcliffe that I felt very enthusiastic with. Cutcliffe (2003) suggested that there are techniques and mechanisms of exploring what we have in our minds. One of them is the use of the reflexive diary throughout the whole research project. In the same vein, Ahern (1999) argued that bracketing is a reflexive process as objectivity is not feasible or desirable in all cases and suggested a reflexive journal.

In addition, Ahern (1999) suggested a well structured approach to reflecting for research purposes which is thought to be beneficial to less experienced researchers. I looked at her suggestion closer to see if I could benefit by its use. In an early stage though, I found out that it could be an obstacle in performing reflection as it would put my thinking into predetermined structures to be expressed as well as explored and I could miss reflecting on other issues that might not be included in the proposed tips.

Moustakas (1995) described epoché as a meditative procedure, done before conducting any interview, which is repeated until the researcher reached closure, that is felt when there is nothing more that could be thought or said on the issue. Then the researcher labelled and wrote the prejudgements and preconceptions and read them repeatedly until consciousness felt released from them. The researcher was then ready to perceive the issue under investigation as new and be open to the information given by the respondents. Each of the above authors, Moustakas, Ahern and Cutcliffe, presented their personal ways of approaching bracketing. What they had in common was that this was a process that should continue throughout the study and it required reflexivity.

It was apparent that the way of performing epoché has become a personal choice. Thus, I needed to search in myself and find out how would I be able to do it. I started by writing down anything that came into my mind and was relevant to the issue I investigated. Soon I came to realise that the volume became too large to handle and writing wasn't so handy. Thus, I thought of trying tape recording myself. So on the



1<sup>st</sup> of June 2003 I wrote:

‘Today I read a very interesting suggestion of how to do it. Moustakas suggests that the researcher should record any thoughts, opinions, knowledge that has in mind before starting the data collection. I think it was very useful as I was finding a bit difficult to do it in writing. Sometimes you can think faster than you write. I tried typing but I was not very comfortable, hand-writing was better but still not great. I have nothing to lose if I try tape-recording. Moustakas suggests a meditative procedure before starting. I tried it and although it helps to concentrate before starting to record it is not really something I like. I do not think I am going to use it.’

On the 3<sup>rd</sup> of June of 2003, after testing the idea of tape recording myself in order to perform epoché, I noted:

‘I tried the new idea of tape-recording myself. I have to admit that it was a lot more beneficial for me. Not only it was faster but it was easier to come closer to what I knew for the matter. I had thought to tape record myself several times as I did not exhaust myself in one go.’

I was actually surprised of how many thoughts were there. I had so many preconceptions and experiences myself on participation and old persons. This process was repeated several times.

When I finished my first tape recording I let a couple of days to pass by and I heard the material again. Then I realised that I needed to add a few things. This was repeated several times, up to the point I felt that there was nothing more to add. As I kept hearing the tapes I realised that these recordings actually made me more aware of myself as a novice researcher, a nurse, a Greek, a student, a user of the NHS, a person that has a family with potential health problems, a woman, a person that will inevitably grow older, a person that inevitable has likes and dislikes, hopes and fears. At this point I felt that I was aware and I could consciously put aside myself and have a clarity of the subjectivity of the participant.

I kept the tapes so that I could hear to them again and keep adding when necessary, as the study proceeded. I also decided to keep a reflexive diary and field notes to assist my effort (see p. 100-101). This material of my recordings although it was interesting, it is not the focus of my research study thus I will not refer to it extensively but rather acknowledge significant points when necessary for issues of rigour.

### **3.9 Choosing the data collection method**

Deciding that I will be using phenomenology and follow the Husserlian approach has brought up another issue of consideration for me, discover which would be the appropriate data collection method. As Pollio et al (1997) suggested when human experiences are the focus of research then the method should be appropriate to the topic but also rigorous to its use. Moreover, in phenomenology the method has to give respondents the opportunity to express themselves freely and be able to offer a detailed description of the experience.

Webb (2003), in her presentation to the Journal of Advanced Nursing of the guidelines on how to report qualitative research, clearly stated that only unstructured data collection methods are acceptable for phenomenological studies. Similarly, Anderson (1991), Moustakas (1995), Polit and Tatano Beck (2004) pointed out that phenomenological studies primarily use in-depth interviews as their preferred method of data collection; diaries or written reports can also be used.

Arksey and Knight (1999) mentioned that interviews in social sciences aim to uncover the perspective of the person been interviewed, and explore meanings. Punch (1998) also argued that interviews are the tool that a researcher can use to grasp people's perceptions and meanings and therefore understand others. Rubin and Rubin (1995) suggested that interviews can be used so that feelings and thoughts can be revealed. In phenomenology more specifically, their purpose is to understand

shared meanings by getting from the interviewee a vivid representation of the lived experience (Sorrell & Redmond, 1995)

On the other hand, Robson (2002), Bechhofer and Paterson (2001), Kvale (1996), Rubin and Rubin (1995) pointed out that interviews are not unproblematic and that other methods of data collection need to be considered as well. Interviews tend to be time consuming and moreover the costs tend to be significant (Gillham, 2000; Robson, 2002). Gillham (2000) mentioned that factors like travelling for interview purposes, and the time needed to carry out a pilot or transcription is often underestimated. In order to make a research design feasible when interview data are involved, the researcher has to judge if the interviews are necessary. I was quite concerned with the above issues as I had time and money constraints as a PhD student.

Moreover, in this study old persons would be the population that would be studied. That meant that some more issues were to be taken into consideration. It is suggested that old persons are more likely to have practical problems like visual impairment, the phrasing of questions, illiteracy, and the duration of recall required (Ebrahim and Kalache, 1996). Thus, the above mentioned option of keeping a diary and written reports did not seem to be feasible in all cases. Therefore, interviews seemed to hold considerable advantages for this study as they suited the methodology and the population that was going to be researched which posed some challenges that I could overcome by interviewing.

Corbin and Morse (2003) suggested that there are three types of interviews: unstructured, semi structured or closed-ended. These have considerable differences in the distribution of power over the interviews, maintaining control and the initiation of interaction. In the case of unstructured interviews the participants have the power to set the agenda of the interview and they are in control of the interview process. This is not the case in the other types of interviews. In the semi structured interviews, the interviewer sets the agenda and determines the issues that are going to be discussed. The interviewee can however determine the depth of the information

provided and the questions that are answered. Although the researcher controls the discussion in the beginning, in the course of the interview the control shifts to the interviewee. In the closed-ended interviews, the researcher maintains control over the information that is going to be collected by setting the agenda and determining how questions are answered. The participant control is limited to deciding if they want to respond and whether their answer is sincere.

It is apparent from the above that phenomenology cannot be congruent with any other type of interviews than the unstructured one. Unstructured, in-depth interviews give the opportunity to the respondents to give their own account of the experience under study. This is evident in the majority of phenomenological nursing studies as well (for example, Baillie, 1996). Rice and Ezzy (1999) used the term 'phenomenological interviews', defined as in-depth unstructured interviews that follow the phenomenological approach. When a phenomenological approach is concerned, calling interviews phenomenological can be justified by the philosophy that underpins the study as a whole.

The Husserlian phenomenological approach poses on the interviewer the challenge of bracketing, which means that a researcher should be engaged in the interview and at the same time perform epoché (see p 114-115). Phenomenology following the Husserlian tradition is a 'scientific' approach that is based on reduction and bracketing while interviewing is based on the interaction with the interviewee and it is a more 'hermeneutical' approach of the qualitative methodology. That means that I need to apply epoché as far as I am concerned in order to extract their views and experiences uncontaminated by my views and experiences. In my detailed account of the interviewing process I will present how I applied that into practice and overcame difficulties that are associated with that.

### **3.10 Ethics, study approval and access to the setting**



Having decided on the methods and methodology that I would follow, I needed to look at the ethics of the study and eventually start performing the study. In order to start the study I had to gain the approval of the relevant research committee and access to the setting. It is accepted that for research to be considered worthwhile, certain conditions have to be met: there must be clear reasoning for doing the specific research project and careful consideration of the methodology in order to maximize the benefits (for society and nursing in this case) and minimize the risks for the participants. In addition, each researcher has to demonstrate that they are aware of the potential harm as well as the benefits, and take any possible measures to ensure anonymity and confidentiality throughout the research and until the publication of the results (Raeve, 1996; Sahini-Kardasi, 1997).

Marshall and Rossman (1989) gave significant emphasis to the issues of entry, reciprocity and ethics. I thought carefully about these issues and tried to tackle them with the appropriate approach following some fundamental biomedical ethical principles that remain unchanged. These are: respect for autonomy, doing no harm, doing good and acting justly (McHaffie, 1996).

Greece as a member of the European Union has been influenced in the process of obtaining approval for research, by the European Union's conventions and international declarations such as the Declaration of Helsinki (Sahini-Kardasi, 1997; World Medical Association, 2001). Ethical approval for the study was sought from the local Health Board Ethics Committee for each of the four Open Care Centres that were approached (appendix C). The first step in gaining ethical approval was to contact the committee informally and ask for advice as far as the requirements and the procedure were concerned. Following this, a copy of the research proposal and the appropriate application form was sent in order to gain approval and conduct the research project.

In addition to the research proposal, the participants' informed consent was required by the committee. All of the information and documents given to potential participants were in lay language, explaining the potential risks and benefits and the

requirements of participation. All of the above were discussed with the participants and the researcher pointed out that even if they agreed to participate, they could withdraw at any time.

Confidentiality and anonymity are also protected by legislation (European Convention on Human Rights and Biomedicine) and the researcher made explicitly clear that these would be respected throughout the research until the publication of the findings (Sahini-Kardasi, 1997; Giannopoulou, 1999).

In order to facilitate the research, gatekeepers, in this case the managers of the Open Care Centres, were also approached and informed about the research (Cormack, 1996; Sahini-Kardasi, 1997). In addition, the nurse, who is the professional gatekeeper, was also approached as her co-operation was required to gain access to the records in order to approach the potential participants. As Mander (1992, p1461) mentioned,

‘the involvement of nursing and medical managers depends on the orientation of the study’.

Once approval from the ethics committees was obtained, I could proceed and seek the informed consent (Appendix B) of the participants so that they participate voluntarily. Voluntary participation means that the participant has fully understood the benefits and risks they might face if they participate in the study (Holloway & Wheeler, 1996). To ensure this was the case, I handed out an information sheet (Appendix A) to people that were contacted to participate in order to describe the issue under investigation, the aims, the method used, the time required and how anonymity and confidentiality would be protected (Polit and Hungler, 1997). In this case, the comprehension of the information given was an issue of particular importance as the participants were old persons. To reinforce comprehension, I discussed the information sheets with the potential informants at their convenience and allowed them enough time, in order to give them the opportunity, to ask questions and think whether they wanted to participate in the study.

An issue to which I gave significant attention was the issue of withdrawal. Unstructured interviews and the intimacy that they create can generate a number of complicated issues that might cause the participant to want to withdraw. Therefore, it is essential to make clear to the participant that they can withdraw from the research project at any time (Morse & Field, 1996; Halloway & Wheeler, 1996). In the case that they decided to withdraw from the study I made clear that they had the following choices: to have no further involvement but allow me to use the material already obtained; to withdraw their consent and give no further information for the research project or finally to have no more involvement and also withdraw their earlier interview. These choices had to be clarified as the study would involve two sets of interviews.

I had also thought about, and discussed with the ethics committee, the prospect of a participant asking for help. According to the ethics of the nursing profession in Greece (Giannopoulou, 1999), I should offer help and support in such a situation. With the participant's approval, I could also refer to the Open Care Centre as it provides a variety of services such as social care, medical care and physiotherapy. Ethical approval justified my presence in the Open Care Centre in order to perform the interviews but it did not include undertaking the role of the professional advisor. Thus it was essential to be able to perform the interviews in such a way that I would not cause any problems to the participants and be able to refer them to the appropriate services if a problem came to my attention and they asked me for help.

In addition, the interviewer has to be aware of their role and make this clear to the participant. For this study, it was also important that participants realised that the relationship between interviewer and interviewee could not be a continuing relationship as the participants were older people and should not be misled to develop unrealistic expectations of the process.

Moreover, the implication that needed careful consideration was the possibility of contaminating the data by changing my role from that of the researcher to the one of the professional advisor. It was essential to make the participants realise the

distinction and for myself to be aware of my role so that I do not contaminate the data.

Names and any data acquired from the study will be kept confidential and nobody but myself will be able to recognise the participants' identity. To ensure anonymity, tapes of interviews will not carry names but letters from the alphabet and the matching list of names will be stored separately from the tapes. Tapes will be erased a year after the research has finished, according to the requirements stated by the ethics committees.

The detailed description that qualitative research employs should not reveal the identity of the participant. Therefore, special precautions are taken in order to guarantee anonymity and make sure that the participant cannot be identified by anybody other than the researcher. Morse & Field (1996) as well as Holloway & Wheeler (1996) proposed changing minor details (for example age of all of the participants by two or three years) so that the informants cannot be recognised. In this case the participants are not recognisable as no information revealing their identity is given (the Open Care Centres are not named, age, names and personal details are not given).

Confidentiality is another important issue. In this case, confidentiality suggested that I would keep confidential what the participant wanted and if I faced a dilemma of whether something should be published or not, the decision would depend on the participants' wishes (Holloway & Wheeler, 1996). This is particularly important as participants tend to share confidential information relating to their health condition (Morse & Field, 1996; Holloway & Wheeler, 1996) with a researcher during the interview and sometimes even more intimate information.

Corbin and Morse (2003) argued that there is always the risk of jeopardising anonymity and confidentiality. They argued that there is always the case that someone reading the report can recognize a participant from the quotes used in the analysis as qualitative research is based on thick description. This is a concern that



made me feel very apprehensive of these issues. However, whilst it seems to be a valid concern in research that investigates uncommon issues, there is no evidence in the literature that this has been the case in nursing research. In addition, I did not feel that my study encountered such uncommon issues that could single out any one person. Despite this, as I would recruit participants from four different Open Care Centres, I decided not to mention the names of the Open Care Centres or any other information that could reveal the participants identities.

I made every effort not only to satisfy the requirements posed by the ethics committees, as an obligation to be able to perform the study, but also show genuine interest for the persons that took part. I tried to be understanding and supportive and treat everybody as persons that deserve my full attention. I tried to keep in mind that the study would mainly benefit me and nursing, not the participants' immediate future. Therefore, I would be grateful for their help and make sure that they were fully aware of my gratitude for their co-operation. This was especially important, as they offered me not only their time but also a window to their thoughts and experiences.

### **3.11 Recruiting the participants, choosing the right sample**

The research question itself indicated that the participants would be old persons living in the community. Nonetheless, 'old age' is an imprecise term and may mean anything from 60 years up. The term 'community' is also difficult to define in the context of health care as pointed out in Chapter 2 (see p. 56-59). It can be perceived as a geographical area with well defined boundaries, or it can be perceived as the sense of community that people who belong to the same group can share by identifying themselves on the basis of common interests, values or identity. Therefore, a community can be an ethnic group or a health district (Zakus and Lysack, 1998). Other writers researching the issue of patient participation in the community consider community as the setting outside the hospital, or any other form

of health care institution (Kirk and Glendinning, 1998). In this study, community is considered to be the setting outside the hospital.

Bearing in mind that I would undertake a study aiming to explore in depth a phenomenon, I focused on deciding on the sampling method that would give me the opportunity to reach saturation (see p 129). After researching the literature regarding sampling, I decided to use purposeful sampling. According to Parahoo (1997) and Polit and Tatano Beck (2004), this is the sampling technique in which a researcher by design recruits participants who are thought to know the subject under investigation best. Therefore, they are considered to be the best informants. In addition, as Morse (1991) mentioned, in purposeful sampling the participants are selected according to their knowledge about the topic under investigation. Coyne (1997), an experienced researcher, similarly suggested that the participants should be people providing rich data so that an in-depth study can be achieved.

In qualitative research, in general, the sample size is small. This does not undermine the study as the aim is an in-depth investigation of the issue that is going to be achieved by the selection of informants who can give information about the subject under investigation. In addition, even though generalisability is not considered an essential element of rigour in this research paradigm, it is debated in the literature that generalisability in qualitative studies is ensured by appropriate participant selection (Morse, 1999). Johnson (1997) pointed out that in qualitative research the concept of generalisability has been replaced by the concept of transferability, which means that knowledge can be transferred across settings. In this case knowledge is transferred across settings.

After careful thought and consideration I decided to recruit the participants (initially decided to recruit fifteen to twenty five participants) from the nursing records of the Open Care Centres that old persons in Greece join when they reach a pensionable age (65 years old and older). As discussed in the introduction, the Open Care Centres are financed by the state and implemented by the municipalities. They provide a range of services: psychosocial support, nursing and medical care, physiotherapy,

health education and prevention activities (see p. 10). Therefore, these are places where I could recruit old persons living in the community who would have experiences regarding participation in nursing care.

The participants were chosen according to whether they had experienced the phenomenon and they were willing to talk about their experiences. In this case I selected old persons who were capable of communicating. Confused people or those who suffer from a disability that affects verbal communication were excluded. Old persons that were not able to give informed consent for the study were excluded too. Illiterate persons were not excluded but they were informed verbally in detail and relatives were invited to be present to offer their support to the participant (Harris & Dyson, 2001). Through the catalogues of the Open Care Centre, participants were approached and asked if they would meet me to be informed about the research, and, if yes, give their consent.

I reached the potential participants personally at the Open Care Centres. For feasibility reasons I aimed to interview fifteen to twenty five respondents. Initially I attempted to perform five interviews in each Open Care Centre. My aim was to reach saturation (which means that no new themes and information come up) and I had considered the option of going back to the Centres for further interviews if I did not reach saturation of my sample. If again an adequate number of participants was not reached then another Open Care Centre would be approached. Marshall (1996), in his paper regarding samples recruited for qualitative studies, made a strong argument concerning the sample size. He argued that the sample should be large enough to answer adequately the research question. This becomes apparent with time as data saturation is gradually reached.

The study took place within one municipality, so that I could have easier access to the participants, as well as reducing the cost of the study and the time required to conduct the research. Open Care Centres were randomly approached in both rural and urban areas within the same municipality. They were not chosen from the same place as this could have resulted in research of the phenomenon becoming overly

focused on one area. Kyriakidou (1995) has pointed out that differences can be identified between the city of Athens (the capital) and other areas in Greece regarding health care. Curtis et al (2000, p1002) argued that the design of qualitative samples aims to

“make analytic generalizations (applied to wider theory on the basis of how selected cases ‘fit’ with general constructs), but not statistical generalizations (applied to wider populations on the basis of representative statistical samples)”.

As explained earlier, transferability is what can be achieved in qualitative research. In this case, I decided to investigate the phenomenon in communities that are representative for industrial and agricultural, rural and urban communities. Therefore, by including in the research participants from a variety of areas I did not aim to obtain a ‘representative sample’ nor to generalize the findings but rather to achieve an in-depth study of the phenomenon in Greece.

### **3.12 Choosing the right setting**

The decision regarding the setting had to be taken in the light of my data collection method. There are different challenges posed by different methods. In this case, I had chosen to use unstructured in-depth interviews. Morse and Field (1996), Mays and Pope (1997), Parahoo (1997) and Polit and Tatano Beck (2004) mentioned that the interviewer should aim to create a setting in which interruptions would be minimized or avoided, confidentiality could be safeguarded and the participant would feel comfortable enough to have the interview. Therefore, I decided initially that the participants would be asked to have the interviews conducted at their homes, and I informed the participants that a quiet environment without disruptions was required.

This was my initial decision, which was later reviewed. In the first Open Care Centre to which I gained access, while discussing the details of the study, the manager offered me the option of performing the interviews at the Centre in a quiet room that



was available. There are researchers who argue that allowing participants choose the setting for interviews can make them feel comfortable enough to talk about their experiences (Gorden, 1975). He argued that the setting can affect the interviewee's perception of the interviewer's role as well as their own role. The home setting can be a safe environment for the interviewee but could also make them defensive (if their home is not well cleaned for example) or it may not be able to provide privacy because it might be overcrowded (Gorden, 1975).

According to Marshall and Rossman (1989), a qualitative interview is more like a conversation serving a purpose; the creation of a comfortable atmosphere over which the participant has control is thus considered to be helpful. Therefore, it is more appropriate to be conducted at the participants' homes. Considering the advantages and disadvantages when deciding on the setting of a phenomenological interview, there are considerable benefits when the interviewee feels in control, therefore, the option of allowing the interviewee decide could be more beneficial for the data collection process. After viewing the room, in the Open Care Centre, and testing both options in the pilot, discussed next, I decided to offer the participants the choice of the setting between their homes and the Open Care Centre.

### **3.13 Performing a pilot study**

One of the most important parts of my study was the pilot study. After having decided on the research design I decided to perform a pilot study. This was an important part of the research process as the research design was put into practice. I identified weaknesses of my study and this played a significant role in making decisions regarding changes that improved my research process. It was an opportunity to pilot the interview process that was considered challenging. The pilot interviews gave me the opportunity to experience the reality of conducting interviews for the issue under investigation and refine my implementation of the method of data collection and management.

According to Gillham (2000), practising interviewing as a skill, and piloting the interview as a process that needs to be refined, are two different things. Furthermore, he proposed that these two functions can be combined in order to improve the quality of the data collection process. This is a fine point that I felt that I needed to take into consideration as a starting researcher. Practising has to do with the skills, while piloting with the content. As Gillham (2000) suggested, this is an opportunity to examine issues that might not have occurred to the researcher when designing the research. He also proposed that during the pilot a content analysis would benefit the design of the interviews.

At the beginning of 2003 I gained approval in one Open Care Centre and I decided to start performing my pilot interviews. This was a very crucial time of my research project as I started to put my design into practice and I had to face the challenge of field work. At this time, I felt the psychological strain that starting researchers feel when trying to implement their research designs, especially within the limits of a PhD study program. The following extract from my reflective diary reflects this strain; it was written in Greek and I then translated the text into English (02/02/2003, entry in my diary):

'I feel like a lot of time has passed searching the literature and writing reports but without actually starting the fieldwork. Since I have decided my research design the preparation for the committee to gain approval for my research has been very stressful. The idea that I have to obtain approval from four different committees started making me feel very stressed. I am very concerned with the feasibility of my timetable. I am afraid of delays that were not visible when I started designing my study. Maybe the best idea is that I start with one Open Care Centre and get on with the pilot interviews while I am working on the other approvals. I feel that I will not do justice to my data if my fear gets into the way of the implementation of my study.'

As far as the time-table of the pilot interviews was concerned, I negotiated access to start on the 10<sup>th</sup> of June 2003. We initially agreed to a period of ten days to do my pilot interviews and the ethics committee also agreed that the period could be

extended if more time was required. They also agreed that I could have access during August and September, for the first interviews of the main study.

For the pilot study I planned to conduct two to four interviews (Greece) all in one Open Care Centre. Finally, I conducted four interviews of which one was unusable due to poor sound quality. My first interview tested me as it was an emotionally challenging one. By being prepared though I found myself ready to respond without being caught by surprise.

In this case I had to deal with a very emotional response to my research question and feelings of distress. I had feelings of guilt for asking a question that made the participant upset as I would be directly benefited by this study but I knew that this study would not directly benefit the interviewee. Although I had followed the required process to obtain his consent, that still did not make me feel at ease. I had to remind myself why I was there and put my feelings aside to be able to continue the interview and ask questions while at the same time I had to use the knowledge I had obtained regarding the ethics of performing research. Therefore, I gave the time to the interviewee to decide if he wanted to continue the interview and pull himself together again.

When I finished the interview I felt the need to go back to my tape recordings, listen to a few parts again and practice epoché again. I came across my own experiences and my own motives for performing this study. The big question for me then was how much had I influenced the data obtained. If I did not have these feelings of guilt I might have probed deeper. I realised at this point although I had practiced epoché I still came across something that could influence the data collection. Another point that made me concerned was how would that reflect in my data analysis.

Another issue that made me feel uncertain was the issue of probing. I made the beginning question, and then how could I probe without making awkward comments, keep the discussion going and at the same time not ask leading questions. In the second interview I realised that I had to make an effort to keep the conversation

going and that participants felt nervous as well (see p). Interviewing made me nervous, but the second interview was a bit more difficult because of my first experience. At the end of the interview though I have to admit that I felt more relaxed. I became aware though of the fact that I was influenced by the previous interview and that could influence my data collection. Progressively, though as this was something anticipated I could handle it better. The third interview was easier from these aspects.

Other issues came up as well, participants proposed to stay outside in the yard to have the interview. Initially, I did not see any problems with that as I was reassured that it would be a relaxing environment and I felt that I would be rude if I did not allow the participant to sit outside on a hot day. Nevertheless, it proved to be disastrous for the sound quality of the tape recording and the interview in general. Cars and motorcycles were passing by and neighbours were greeting and chatting to my interviewee during the interview. I learnt a good lesson as to being flexible in issues that have to do with the quality of my data collection. This interview was beneficial because I realised the importance of the right setting for the interviews. It was however impossible to use the data from the interview in any other way due to the poor sound quality.

Furthermore, I had read about the impact of appearance in interviewing and recruiting but I still was not certain of what would be right in my case. I tried both formal suits and more casual clothes and I was amazed by the difference in the attitude towards me according to the way I dressed. When I was wearing a suit and was more formal and professional in my attitude during my contact with the respondents I was more than satisfied with the results of my meeting. Therefore, I decided that I would employ a professional appearance and attitude. Wenger (2002) argued that the way of dressing is important and old persons seem to prefer the modest and conservatively dressed people to give interviews.

This pilot study proved to be a very stressful procedure as time was my main concern. The pilot was conducted during the build up to the 2004 Olympic Games in



Athens, and the heavy traffic and constant changes to the streets in the area made travelling an unpredictable adventure. I realised that I could not even estimate the time that I would need to do all the interviews if the participants were in different areas and I would also have difficulty being punctual for my appointments. Time management was an issue of concern for me during this process.

The interviews were conducted in Greek and tape recorded. After the interview the tape was labelled and dated, I listened to the tape again and transcribed the interview into Greek. I transcribed the data as it reduced the cost and helped me become more familiar with the data. For supervision reasons the full text of the interviews was translated into English. The analysis was done in Greek and was also fully translated into English.

The translation was double checked as the meanings had to be accurately translated and understood due to the nature of the research. A bilingual professional translator was thought most appropriate for this and it was indeed a very useful solution. However, I realized that I was the most appropriate person to do the translation as sometimes the translator gave a different meaning to the participants' words without having the context in mind. The translator helped to make sure that I was indeed using the most appropriate word and by being bilingual I made sure that I had the best translation, as I have already argued that translation is done across cultures (see p. 104-106).

Although content analysis after the pilot is considered to be beneficial (Gilham, 2000), in this case a full content analysis was thought to threaten epoché. In addition, as my analysis progressed I realised that performing the analysis made me more aware of the expected findings in the next interviews. This posed a considerable methodological difficulty as it was important that I go to the next interview without having any preconceptions regarding the issue under investigation. I realised that a full detailed description of the phenomenon at such a premature stage would damage the quality of my future interviews. In addition, after searching the web for phenomenological studies that had used pilot interviews, I did not come across the

use of content analysis as part of the pilot. Therefore, I did not take my analysis further than the third step.

This included the reading of the participants' interviews to acquire a feeling of them, the extraction of significant statements and then formulation of meanings (Colaizzi, 1978). Another issue that I tested was the planned system of data management. I realized that it would be difficult to transcribe the interviews on the same day as I had to travel a great deal. Therefore, it would be more convenient to do it the next day. Although I had to be flexible about it, I found it mostly helpful as the interview was still fresh in my mind and it even helped my analysis as by transcribing the interview I was more accurate in my field notes. In addition I felt closer to my data.

The pilot study proved to be very useful as it revealed some issues that I needed to resolve and it gave me more confidence in performing the study. I felt ready to start the study and more competent to deal with the difficulties that might come up as the study was progressing. On the other hand, it was an experience that made me feel more aware of the challenge that phenomenology posed on me.

### **3.14 Data collection: performing the interviews**

Gillham (2000) pointed out that even unstructured interviews have stages: introduction, opening question, central body, closing the interview. Others like Corbin and Morse (2003) have suggested that the interviews are divided into the tentative phase, the immersion phase and the phase of emergence. My experience of interviewing for this study has shown that interviewing could be divided into the following phases: before the interview, during an interview, ending and after the interview. Häggman-Laitila (1999) suggested keeping a diary. Seidman (1998) also proposed that interviewers take notes during the interview so that they concentrate on what is said and will be able to explore issues more when the time is appropriate.

This technique is also described by Seidman (1998) as the echo. I actually decided to keep field notes and keep notes after the interviews.

### **3.14.1 Before the interviews**

An introduction was prepared that would be the same for every participant and allow them to ask questions (Sorrell and Redmond 1995). For that reason I had prepared an information sheet that included the information I gave participants before starting the interview. During the introduction the interviewees I explained why they were being interviewed, why the interviews were being conducted and how long they would take. This was dealt with while informing the participant in person, before obtaining consent but they were told again before the interview started. Although participants were given this information previously, before obtaining consent, they should be told again before the interview started (Gillham, 2000; Parahoo, 1997). I told participants the title and the aim of the study. It is discussed in the literature review that participation is a term often presented as having the same meaning with the terms involvement, collaboration, and partnership. In this study I will ask about participation and I will let the participants talk about what they think relevant and I will not interfere.

Then I reminded them that they could withdraw at any time without being penalised in any way and stressed the issues of anonymity and confidentiality. I also reminded them that I would tape record the conversation, and asked for permission to do so. I would start recording after they let me know that they are ready to start talking. I also let them know that I intended to use half an hour to two hours of their time and I needed a quiet environment without interruptions.

What the interviewee gains (Corbin and Morse 2003) from the interview period is an important issue, as well as the bargain between the researcher and the interviewee (Parahoo, 1997). People take part in a research project because they anticipate some kind of reward (Parahoo, 1997; Corbin and Morse, 2003; Polit and Tatano Beck,

2004). In this study they would be indirectly benefited by the contribution of the study to the enhancement of nursing knowledge and consequently practice. This reward could also be coming to terms with past experiences and events, obtaining information, or just talking and being heard in a sympathetic and non-judgemental way.

Before the interview I took the time to make sure that the participant had clearly understood what the study was about and make sure that practicalities of the interviews were well understood. Furthermore, the time I spent with the interviewees before the interviews was very constructive as I felt that I established the grounds for a successful interview. It was an opportunity for us to engage in small talk and get to know each other; the interviewees could also see how interested I was in the study and get an idea of how I may react to their views. During the interview I asked them to talk to me about their experiences and thoughts, therefore I would like to have created a comfortable atmosphere.

In addition, Burgess (1984) and Corbin and Morse (2003) suggested that the interview could be benefited if the interviewer observed the interviewees before the interview so that non-verbal communication can be better understood. Before starting the interviews I spent some time at the Open care Centres to recruit participants and I used this time to familiarise myself with the participants and brake the ice between us before the interviews. I couldn't say though that I could better understand their non-verbal communication.

### **3.14.2 During the interview**

Kvale (1996) suggested that the first minutes of the interview determine the quality of the rest of the interview. The informants want to get to know the interviewer and it is beneficial for the interviewer to allow this as it will make them more comfortable talking about their lived experiences (Kvale, 1996). Moustakas (1994) also suggested that in phenomenology an interview should start with a social conversation in order



to create a friendly and relaxed atmosphere.

Kvale (1996) also proposed that the researcher should give a few moments to the interviewee to focus and then describe the experience. As Holloway and Wheeler (1996) pointed out, if the researched topic is stressful it is probable that the participant will express anger or sadness (Morse & Field, 1996). Russell (1999) questioned the ethics of research that brings up issues that cause distress to frail people. Although my study did not seem to touch on so-called sensitive issues, participants still became emotional when their narratives were drifted towards emotionally charged memories.

In such situations it is not possible to remain neutral. All people, myself included, have experienced loss, illness, grief and distress, thus it is difficult not to become involved with the story. I have to admit that I found it difficult to continue the interview sometimes and I gave some time to the participant to overcome the overwhelming feelings that arose. I always gave the option to the participant to change the subject, or even stop the interview if it became too difficult. On one occasion I felt that I should not probe further as I could see that I would cause further distress to the participant and finished the interview earlier than I would have in different circumstances. I considered it out of place to leave a participant distressed without, at least, making sure that I offered any comfort or even assistance to make them feel better.

### **3.14.3 Ending an interview**

The introduction determines the course of the interview but the closure affects the interviewee more. The interviewee is the one who determines the ending of the conversation as it is made evident that they do not have any more information to add. For the closure, a summing up is needed and also, a question that will give them, the opportunity to add anything else that they consider relevant or important to the issue which has not been mentioned. Kvale (1996) suggested a debriefing on the issues

that have been discussed and allowing some time at the end of the interview so that some issues can be brought up unofficially. Seidman (1998) mentioned that the participants might even become tearful. Thanking them for a valuable contribution is a standard procedure and asking them if they want to be sent a report when the findings are available usually shows that the researcher values the contribution (Gillham, 2000). Switching off the recorder is the final act that shows that the interview is over.

When the tape recorder was switched off, the participants felt more at ease and I had the opportunity to discuss the issue and offer them information or even suggest appropriate professionals that could help them further. In addition it was an opportunity for them to ask me more questions and even give me additional information that I was not told when the tape recorder was switched on. A friendly discussion after an in-depth interview is necessary to release tension and assess whether the participant is in a good condition to be left. In addition, I reminded participants that I would return for a second interview at a later date.

An example is the following interview incident that an appointment was rescheduled. The fact that she had to change the appointment made her to feel bad as if she disappointed me. She seemed to be a bit run down (I assume) because of the problem she dealt with and I wanted to give her some more time before the interview but she insisted to have the interview as soon as possible. She gave me the impression that she would be offended if I did not interview her as soon as possible. I re-assured her that she had the right not to proceed with the interview if she did not feel like it or change the date, as long as the new one was convenient for both of us.

After the interview she seemed to be very fragile but I thought that this had to do with the problem that caused her re-arranging the interview as even before the interview she seemed to be run down. I stayed with for almost an hour and a half after the interview, until her husband came back. I told her that if she needed to talk I would be glad to listen and she said that it is her 'old age that makes her silly' and she tried to laugh. She wanted to show me pictures of her family and she wanted to

know how is life for me abroad. Gradually she looked better and when I left she asked me to visit her again with my pictures. I told her that I would be glad to and left. I am aware of the fact that I should not give promises to the participants that I cannot keep but in such cases I am glad to see the participants again and not forget about them as 'objects' of my research. In addition the fact that I 'visit' them at their houses makes them see me as a person close to them and the whole process a bit like socialising and I gained the impression that they would feel hurt if they considered the relationship strictly 'professional'.

### **3.15 The challenge of unstructured in-depth interviews when using phenomenology**

It is often emphasised in the literature that qualitative interviewing is not described in detail according to the different qualitative methodologies (Sorrell & Redmond, 1995). Phenomenology poses additional difficulties to researchers when interviewing. Lowes and Prowse (2001) emphasised the fact that the specific philosophy influences the role of the interviewer as well as the process of the interview. According to the Husserlian phenomenological approach, the preconceptions and beliefs that the researcher has prior to the research should be acknowledged and bracketed (Moustakas, 1995). In addition, Jasper (1994) suggested that interviews used in phenomenology have certain characteristics that require the researcher to be in control of their mind and reactions so that the informants will provide their own perceptions and experiences. According to Häggman-Laitila (1999), one of the main concerns of the interviewer when conducting interviews in phenomenology is to overcome their own views.

Bracketing during the interviewing process was challenging. When performing the interviews I had to set aside everything I knew about the issue but still I needed my identity as a Greek to understand non verbal communication, and use my social skills in order to communicate effectively with the participants and establish rapport. On the other hand, McCracken (1988) suggested familiarity with the culture can give the

researcher a potential for greater understanding of the issues that arise but it can also predispose them to more preconceptions and biased questions or wrong assumptions about what they hear as they take certain assumptions for granted.

For example, I will describe some of the interaction with one of the interviewees. I arrived fifteen minutes earlier as I did not want to keep her waiting, thinking that they would appreciate it. I was surprised to see her in the kitchen cooking. She told me that she had decided that she had invited her children for lunch, after work and she had lots of things to do, therefore she couldn't be interviewed for an hour. I have to admit that I felt annoyed but I had to see if I could get something interesting from this interview. Both verbal and non-verbal communication made me feel that she was friendly with me, she would not mind the interview but she would not change her plans. Thus, I replied that I would use as much time as she was willing to give me. I knew that in Greece most people finish work at three o'clock and some at two thirty as they start working earlier in the day than in UK, so this would be the time that she would be expecting her children.

During the meeting both verbal and non-verbal communication had shown that she was quite friendly with me but a bit nervous with the recorder. After I reminded her what I would like her to talk about I asked her if it would be fine to turn on the recorder. To my surprise she was focused on other people's care. I let her talk about what she thought it was important and I did not insist on making her talk about her own care. I have to admit that I probed her to focus on herself because I thought that she was not focused. I soon, though tried to be more neutral as I realized that the participant spoke about what she considered relevant and this meant something about her understanding of participation.

After the interview she asked me to stay for lunch. I refused politely. She told me that she liked talking to me and that she would tell her friends all about me if I wanted to interview them as well. I thanked her and told her that her interview was the last for the pilot and that I would approach the rest of the respondents through the Open Care Centre. She also asked me to listen to her recorded voice, which she did.



She showed me her blood pressure machine to ask my opinion of how reliable it is. I replied that I was not an expert but if her doctor and the pharmacist recommended it then she should be sure that it is reliable.

I realised that the issue of rapport is an important issue as too much or too little can affect the data collected significantly (Seidman, 1998). I thought to maintain some distance from the interviewee. The intimacy that is created due to the in-depth interviewing can bring up issues that need to be brought to the attention of the relevant services although this should be done in co-operation with the participant and according to the code of practice. In this case it seemed to be a harmless question but still I needed to refer her back to the responsible professional.

The more interviews I was performing the more I realised that interviewing is not all about the technique but interviewer's role is to enable participants to express themselves. Therefore, the interview process is led by the respondents and the questions derive from the dialogue, aiming at a fuller description of the phenomenon. Burns and Grove (1995) agreed that the role of the interviewer in unstructured interviews is to encourage the participants to express themselves. In this study each interview is set by the respondent and the questions are not pre-specified but rather flow from the dialogue and aim to explore the phenomenon in more detail.

Holloway and Wheeler (1996) argued that research interviews are more than a discussion between two people, as they have the purpose of obtaining information about the issue under investigation by the respondent, which could result in an asymmetrical relationship. The researcher's control over the interview might be minimal but it still exists as the researcher has an issue in mind that needs to be explored.

Mander (1999) pointed out that the relationship that develops between the interviewer and the interviewee is a power relationship. She argued that, in cases where the interviewees have to tell their own stories, they have more control over the interview process. In the same vein, Corbin and Morse (2003) maintained that when

participants are asked to tell their stories, express their views and experiences, they are given control over what is going to be said and how to say it, as well as the order, detail, the duration of the discussion and the depth. They are in control of the content and the process of the interview. They mentioned that the participant is telling a story for an audience, therefore, they tell the interviewer what they would like to be heard.

Nonetheless, I could feel that I had a certain power during the interview as I could influence slightly the course of the interview, through probes or encouragement regarding certain topics for the purpose of my study. Most importantly of all, I did determine the purpose of the discussion.

On the other hand another issue that came up was the shift of the interview process from the interviewee to me as all of the interviewees were asking me personal questions. They wanted to know about my family, my studies, if I was married, if I was happy. Therefore, I felt that I should be prepared and aware of how much I can or want to say as I should not influence their answers and I did not want to spend too much time on myself. It was though an important element of our interaction as it helped establish a trusting relationship with the participants. Corbin and Morse (2003) advised that in order to maintain control of the interview the interviewer has to be certain of what they want to learn from the interviewee, be prepared to ask the right questions and give the proper feedback not only with verbal but also with non-verbal communication. The effect of the tone of voice, dress and behaviour are all factors which have been identified as being able to affect the course of the interviews.

A great deal of care was taken so that they will feel that they are not given a subordinate role and that they are understood and the feeling of empathy is genuine. I kept a low profile initially and gave space to the interviewee to choose how they want to be treated and addressed (Parahoo, 1997; Gillham, 2000).

When a researcher is doing research about old people it is helpful to bear in mind a comment that Wenger (2002) made that they are like everyone else, they just happen

to have been alive for a longer time. Denzin and Lincoln (1998) stressed the importance of how researchers present themselves for the course of the interviews. The way of dressing is important and they seem to prefer modest and conservatively dressed people to give interviews (Wenger, 2002). Gillham (2000) suggested that dress is significant as it shows if the interviewer has made an effort and therefore shows respect for the interviewee (see p. 133).

### **3.16 Debating the use of an aide memoir in phenomenological research**

As I already explained, unstructured in-depth interviews are the most appropriate method of data collection (see p. 119). Nonetheless, during the pilot study I discovered that unstructured interviews are quite challenging. I found myself in the position of having to deal with a participant not focusing on the issue, myself being lost for words and get stressed in my attempt to overcome it and being hesitant to ask because I was afraid that I would ask a leading question or that I would dismiss bracketing. The above issues led to a search of the literature to see whether there was an acceptable way of tackling them.

Nurse researchers (Parahoo, 1997; Holloway & Wheeler, 1996), as well as researchers that explored phenomenology in depth (Moustakas, 1995), did suggest the option of introducing an interview guide or as some others call it, an aide memoir (Parahoo, 1997), to overcome the above difficulties. A topic outline can be used in order to overcome the difficulty that completely unstructured interviews can generate, such as obtaining too much detail or too little information on the issue under investigation or even irrelevant information (Arksay and Knight, 1999). This guide is by no means meant to provide a uniformity to the responses of the interviewees, as this is not in congruence with phenomenology.

On the other hand, Wimpenny and Gass (2000) pointed out that a frame of reference opposes the naivety that can be considered essential for phenomenological research.

Although there are researchers that argue that in phenomenology only the starting question should be asked, like Lowes and Prowse (2001), there are researchers reporting evidence of benefits when guidance was given during the interview. Lowes and Prowse (2001) noted that some guidance during the interview was not only appreciated by participants, it also improved time management and the quality of data obtained.

I thought it would be more appropriate to use a loose guide containing subjects that were of relevance to the actual research question and that I could fit into the conversation in a more natural way. Thus, they could be more useful. May (1991) stated the need for balance between flexibility and consistency. Flexibility is essential for collecting data that is representative of individuals' issues. Consistency at a reasonable level is also essential as terms of the type of questions and the depth required so that conclusions can be drawn.

In this case, an 'aide memoir' was used, so as to overcome any difficulties that might have been encountered if the interviewee could not focus on the research topic (Holloway and Wheeler 1996). The 'aide memoir' included the following subjects: experiences of participation (in maintenance and promotion of health, prevention of disease, adaptation to disability, planning care, evaluation of the received care, decision making); ways of participation; and examples of occasions where interviewees participated or did not.

### **3.17 Asking questions in phenomenological research**

The questions in this study were as brief as possible, phrased in lay language (Kvale, 1996) and open-ended as they can give the participant an area to start from but also the opportunity to talk about what they consider relevant to the subject and important to be mentioned (Seidman, 1998).

Rubin and Rubin (1995) suggested that in qualitative interviewing the researcher



should start with an open question that would allow the interviewee to express what they think. Mays and Pope (1997) advised that an interview should be started with a question that everyone can answer. Jasper (1994) suggested a form of question that can be used to start the interview by asking to describe the phenomenon in as much detail as they can.

The interviewee should then speak until they reach the point they have nothing else to add. In this study, the starting question asked interviewees to give a full description of their lived experience of participation in nursing care, to remember the last time they participated in nursing care, how they felt and what their thoughts had been. Participants were encouraged to talk until they had nothing else to add. Further questions were asked to probe more deeply, appropriate to the occasion.

Furthermore, Price (2002) reported that when participants taking part in her study were just asked a general question without any guiding on behalf of the interviewer, they gave only a short superficial account of the issue under investigation. All these were concerns that I had in mind before starting my pilot study.

As Corbin and Morse (2003) argued novice researchers who use unstructured interviews can run out of questions or ask leading questions. Researchers also might be lost in deciding where to probe more deeply and when not to interrupt. Sorrell and Redmond (1995) suggested that the interviewer use verbal or non-verbal probing in order to encourage the interviewee and obtain more information when needed. Interviewees might feel that their answer is irrelevant if they do not receive the interviewer's approval and encouragement.

Price (2002) reviewed the literature and analyzed the types of probes that are used in interviews. A brief examination of these probes is necessary here as this is a phenomenological study and I needed to make sure that I did not contaminate the data with my remarks and be able to demonstrate it to the readers. Price (2002) presented the following ways of probing:

- Silence: The interviewer remaining silent gives the participants the space to

develop their narratives as they want.

- Repetition: the interviewer repeats the participants' words to encourage them to talk about an aspect in more detail.
- Expressing interest discreetly: periodically the researcher can express their interest with phrases such as 'I see', 'uh-huh' or 'yes'. These can show interest without intervening.
- Directly ask the participant to give more information about a certain subject.
- Asking detailed questions: by asking a long detailed question, the interviewer can indirectly show the participant that a long detailed answer is sought.
- Indirectly prompt the participant to take position: researchers can ask the participants to express their opinion by offering them a piece of information that they know that is going to provoke them to take a position.
- Provoke the participant to share more information by creating the impression that the researcher knows more than he or she actually does.

The last two probes are inconsistent with the Husserlian phenomenological approach as they threaten epoché (see p 114-115). Therefore, I was careful not to use them.

### **3.18 Doing follow-up interviews for verification**

In this study, two interviews would be performed. This was a decision that was taken at a later stage as the method of data analysis that I had chosen required a second interview in order to validate the data analysis (Colaizzi, 1978). This will be further discussed in the section regarding data analysis (see p. 163-164).

The second interviews (verification interviews) could be conducted by telephone or face to face as the first set of interviews. Jordan et al (1980) compared telephone and face to face interviews and came to the conclusion that face to face interviews were preferred by interviewers. It was reported that the lack of face to face contact may lead to communication difficulties as non-verbal communication is not achievable. On the other hand this can be viewed as a way of minimizing researcher bias

(Marcus and Crane, 1986).

Worth et al (1993) chose phone interviews as the data collection method to perform the follow up interviews in their study regarding discharge planning with a sample of old persons. They reported low cost and time requirements. They also mentioned that they were effective as they managed to achieve their aims from the interviews. The main difficulty that they experienced was the communication difficulty due to the hearing impairment that some participants suffered. Other difficulties encountered were participants' inability to recall past experiences, feeling ill, or unwilling to talk about the issue under investigation. In addition, the interviewer loses the non-verbal communication signs that enhance the quality of the data.

I considered the use of phone interviews for a number of reasons. Firstly, as a PhD student, I had limited resources. In addition, I had difficulty persuading the participants to give a second interview that would be tape recorded like the first one. Lastly, this method of data collection is helpful when the interviewer has to conduct several interviews in a limited time and with limited resources. In my case I did not have a large number of interviews to perform, and although time was limited, I could sustain the cost. Therefore, I decided that it was preferable to have face to face interviews that would offer me a better data quality.

Another issue that needed to be considered was the organization of the interview schedule. The verification interview would take place approximately three months after the first one as the last step of my analysis.

During the first interview the participants had been asked if we could meet again a few months later for a second interview. The reaction of the participants was, for the most part, less than enthusiastic, which was a cause for personal concern for the course of the research. Different excuses were given by the participants. Some were evasive in the beginning and they said that we would discuss it again when the time came. Others said that they had said everything in the first interview and they would not wish to add anything else. Others admitted that they were uncomfortable with the

idea of being recorded again.

Options were explored. There was an extensive search of the literature to identify accounts of researchers that used the same method and encountered the same problems (see p. 163-164). Not many articles were found with detailed accounts. Hantikainen and Käppeli (2000) in their study contacted three of the informants to confirm that they interpreted the data in a relevant and accurate way that reflected their experiences. Other studies did not specify the number of the informants that participated in the second interviews. Two were acceptable: to meet with the respondents that were willing to have a second interview or try to approach all of them in an informal way without the use of the recorder wherever they were willing to be met in order to maximise the response rate.

According to Leininger (1985) the use of audiovisual media for research purposes can be difficult, non-scientific or even questionable but they are unquestionably part of the nursing research methods. They are considered to be invaluable in documenting and studying health care. Morse (1991) points out that qualitative interviews can be formal, or informal depending on the study. A variety of techniques are developed to record and store the data. It is pointed out by a number of researchers that the best way is to tape record each interview (Holloway & Wheeler, 1996; Morse & Field, 1996). On the other hand Leininger (1985) clarifies that tape recording the interviews can be done if the respondent permits it and feels comfortable with the idea and that there is an increasing number of people refusing their interviews to be recorded for a variety of reasons. Therefore, it is up to the researcher to use reliable methods of storing data.

In this stage of the study, the interviews would not be tape recorded; instead the researcher would take notes. I had noticed since the first interview that the use of the tape recorder made them feel a bit uncomfortable. Although, tape recording the interviews was desirable I had to choose among the option of having the chance to meet with the most of the interviewees in an informal way or have a tape recorded interview with three to four of them. I decided that validating my findings with the



most participants I could was more beneficial for my study in terms of validity. Therefore, I decided that I would keep notes on my copy of the findings as it was more discrete than having a notebook with me.

In addition, I preferred to be more relaxed so that they would be more open in expressing their views on the findings. I had come across their fear that what is tape recorded has to be carefully thought before said as it would last. They were afraid that there was always the chance to be embarrassed due to the fact that they associated the tape recorder with journalism and making stories public. This is a cultural issue also as there is the widespread opinion that family issues should be revealed only within the family environment. In case something went public that was associated with loose family relations.

The more respondents I managed to meet the more material I would gather to validate my research results. Therefore, I started phoning them. My call was a friendly thank you call. I was also asking if I could call them again to arrange a meeting to discuss my findings. The respondents' reaction pleasantly surprised me as they were positive about it. They were glad that I called them to thank them and they felt valued as I wanted their opinion about my findings. Most of the participants expressed interest for the future results of the research.

The participants were approached to be asked a follow up interview in an informal way through telephone. Two of them said that they were not available at all and they were not interviewed. One the participants who refused to meet was one of the participants that was talking about gardening and flowers. This specific participant appeared to be uninterested talking about my research topic since the first interview, therefore I was not surprised by his refusal.

All of the participants were asked when it would be suitable for them to meet. Then a date was proposed. They were assured that there would be no tape recorder used and it would be an informal discussion informing them about my findings and asking them their opinion about them.

A date for a second interview was scheduled with each participant. The participants were given the option of meeting at their home or at the Open Care Centre. The majority of the interviewees preferred the Open Care Centre as it was well air conditioned and at the same time they saw the meeting more like a social activity than taking part in a research project. I also preferred this option as more than one interviews could be conducted in one visit at the Open Care Centre if possible. That would save me a lot of time. On the other hand I had to be careful with the appointments as I would not like to rush an interview so that I can be on time for the next one.

I started the interview by having a social conversation. I felt that this was appropriate as they were interested to talk about themselves and they wanted to know small things about me. We had already known each other and it would be an unsocial action if I started the interview right away. I started the interview by asking them their opinion about the research findings. I asked them whether these results reflected their experiences, how they felt about it and in which way they felt that they differentiated if they felt so.

I had prepared a copy of a summary of the research results for each participant. They were presented to the participants in order to have a focus for discussion and cover the same topics with all of them. I thought that longer than three pages would be considered tiring to read and less than three pages too brief, considering that they had been interviewed for an average of forty five minutes. I could not present them a full detailed description as they would be lost in the amount of information and I needed more detail than the clusters of themes.

The appearance of the document was carefully thought to make it easy to be read by the participants considering the fact that most of the participants had problems with their eye-sight. The letters were size 14 so that the participants could read it easily. The margins were smaller so that I could include more text in one page. Bullet points and bold were used for emphasis. This arrangement was not significant for part of

them as they were illiterate.

The points that the participant agreed and did not want to talk more were ticked and the points that they had a different opinion were underlined. The comments were written in red ink. I had a copy that had double spacing and a smaller letter size (12) to allow taking notes on it. It was filed with the tape from the first interview and the appropriate code later at home.

I was aware of the fact this is a phenomenological study and bracketing was an important principle to be safeguarded. I had developed ideas and feelings through the transcribing and analysing of the interviews. Although the summary of the findings was there the personal involvement and knowledge is present and some times difficult to be separated. For one more time I used epoché.

In this case the interviews were structured as I needed to obtain information about the same issues (my research findings). I wanted to obtain their opinions on my results and I needed to cover the same issues with all of them. Wherever I thought it was important I probed the respondent to talk more and asked for more details or clarifications.

I tried to follow the same step by step review of the summary of my results and provide the same information to all of the participants. This was a difficult task as some informants wanted to learn more details and some others were not that interested. I preferred to satisfy their curiosity as I thought this was their right and the smallest reward for participating in my research. In the same vein I wanted them to fully understand what I was saying in my summary as then I would get the answer I was seeking.

The interviews lasted from half an hour to two hours. The participants would rather discuss the issue in general and it needed considerable effort to focus. In most cases they were not particularly interested to read the summary and they would rather have an open discussion. The participants would prefer discussing certain points that were

brought up by the interviewer. Therefore, I have to admit that by the time I finished the verification interviews I felt very tired.

### **3.19 Time management when performing interviews**

#### **3.19.1 Managing time in unstructured in-depth interviews**

Although the length of an interview can vary, an approximate amount of time should be stated so that both the interviewer and the interviewee can organize their time (Holloway and Wheeler, 1996). The issue of time is important and it has to be also clearly stated to the participant so that they know and organize their program so that the interview is not disturbed. Mays and Pope (1997) also suggested that old persons might need a break, which might make the interview longer than others. Interviews are frequently longer than with younger participants.

The question though is what the approximate amount of time needed should be. Parahoo (1997) suggested that a qualitative interview can last from thirty minutes up to two hours. In a period of time less than thirty minutes no phenomena can be explored in depth and if the interview lasts more than two hours then it could result in an interview that has no focus on a specific subject. An interesting point that Häggman-Laitila (1999) made was that the interviewees should have enough time to express themselves, therefore the interview has to be given on their terms. However, this is not feasible in most cases as there are time constraints for the researchers as well as the interviewees. As much as they would like to be open to the participants' wishes that might not be possible.

In my information sheet I stated that I would expect the interview to last from half an hour up to two hours. This time scale proved to be beneficial for both the interviewees and the interviewer as the interview was more focused. In addition, the participants wanted to know how much of their time I would use, especially in the



recruitment period when I had not yet established a relationship with the interviewee.

Another aspect of time management is the frequency of the appointments with the participants. Gillham (2000) proposed that one interview every other day would be more easily managed by the interviewer and it would enable the researcher to transcribe in the meanwhile. Having the interview fresh is a factor that can help transcribing. There is though the need of flexibility. There were occasions during this study when participants were not available on certain days and I had to change my schedule and perform two interviews on the same day.

### **3.19.2 Time management in the verification interviews**

The only problem I faced then was the practical aspect of it. As it was summer time the participants were planning of leaving Attiki to go on holidays, a large number of them until autumn. The time management in this occasion was important as the participants had tight schedules. Most of the participants were eager to leave and go on holidays to their holiday houses or to friends and relatives. They were concerned with the coming heat wave as some of them, or their partners, were suffering from heart conditions.

Therefore, I had to meet with them by the beginning of July, otherwise I could meet with them after mid September. That would be a significant drawback as I had a strict timetable that had to do with the deadline to submit my thesis and also my funding which had a certain time limit. Needless to say, time management made me feel very concerned.

Unfortunately a series of events (a heat wave and the European football championship) caused some disruption to the programme of the interviews, which made me feel more concerned about the time management. I had to re-schedule four of them as the participants did not keep their appointments because of these incidents. To my dismay, they did not come for their interviews although they did

not inform me about it and their interviews had to be rescheduled. From one hand side I was dealing with the University that everyone was punctual and on the other hand I was dealing with my Greek participants that were dismissive of punctuality. It was very tiring and stressful to balance and organise my time.

My way of dealing with the situation was to rationalise it. People in Greece are more relaxed about keeping appointments and being on time. Gordon (1999) pointed out that time is, indeed, culturally defined, and gives as an example the concepts of early and late which have a different meaning in Southern Europe in comparison to America. She also pointed out that individuals have also a different approach to time as for some it has an accurate meaning and for others it is approximate. In this case they did not even make the effort to call me to tell that they would not arrive as they were quite relaxed about it. Not keeping the appointment was not considered a serious social issue but it still made me feel distressed.

Nonetheless, I felt disappointment at not being able to meet with the respondents having made the effort to go to the Open Care Centre and experienced increasing anxiety about reaching my goal for the number of participants that would be interviewed for the second time. I was concerned that even though I had put considerable effort into pursuing these interviews I did not seem to be reaching my goal. These feelings were intensified every time that a participant did not appear. I had to continue with the next interview and make an effort to fit the new appointment in my already tight schedule.

Not keeping the appointment, they explained, was due to the special circumstances and to the fact that they were approached in an informal way therefore they did not consider the appointment as a formal arrangement. They thought that if they did not appear it would not be an issue for me. They had not been aware of the importance of our meeting for my research. They reasoned that this was not an appointment concerning my research but rather a visit to the Open Care Centre that we would have a short 'chat' by the way.

Nonetheless, these incidents were problems that had to be encountered fast and effectively. I had courteously to reschedule the appointments and accept the fact that they might refuse to meet me on the next suggested occasion. The main problem was that the four day centres were in four opposite directions so I had to schedule meetings in one of the Open Care Centres at a time. Thereby, if one of the participants did not arrive my whole day was spent there even though I had acquired no data. I needed approximately four hours to come and go home and about one hour and a half at the Open Care Centre even when the participant did not appear. I must admit that travelling with the heat wave was difficult.

They apologised when I called them to let them know that although I was expecting them and they did not come I was eager to see them another day if they could make it. After the second arrangement they were on time and helpful. I felt relieved when my participants turned up and I conducted the interviews.

### **3.20 Data management**

Managing data in unstructured in-depth interviewing presented a potential challenge due to the large amount of data. I had to find an efficient and ethically correct way of recording and storing my data. These were comprised of the interviews, my field notes, data in the form of notes but not tape recorded and my diary (audit trail or reflexive diary as others call it).

A variety of techniques have been developed to record and store data. It is pointed out by a number of researchers that the best way is to tape record each interview (Holloway & Wheeler, 1996; Morse & Field, 1996). After the interview the tape was dated and labelled and I listened to the interview to gain an understanding of the main issues that were raised in the interview. I then started to transcribe the data. That reduced the cost (as a typist was not used) and it helped me become more familiar with the data (Hakim, 1987; Roulston et al, 2003).

As far as the organization of my interviews was concerned, a coding system as advised by researchers such as Parahoo (1997), Polit and Tatano Beck (2004) was used. The names of the interviewees were not on the tapes but kept separately in a file in a locked cabinet. They were in a numerical order, as this was more convenient, and I kept the transcripts in hard copies and floppy disks separately. Furthermore, there was the issue of field notes and notes of data that were acquired when I was not recording the interviews. All these were coded and filed in a locked cabinet. It was agreed that they will be destroyed two years after the completion of the study.

The issue of the data storage is discussed here as it can affect the quality of the data as well as the issue of anonymity and confidentiality.

### **3.21 Choosing a method of data analysis**

In this particular study I aimed to describe phenomena through the participants' perceptions and experiences so that an understanding of the meaning of the phenomenon for old persons living in the community in Greece can be achieved. Thus, a Husserlian phenomenological approach was considered most appropriate. Giorgi (2000) argued that what Husserl and even Spiegelberg (1960) suggested is philosophical inquiry and not scientific. Therefore, if phenomenology is chosen to be used in science, it should be modified to suit the purpose. Giorgi (2000) explained that the 'scientific' phenomenological method is descriptive, uses reduction and searches for meanings or essential structures that are typical. Thus, scientists use a research method based upon the Husserlian perspective.

Husserlian phenomenology is based upon reduction and bracketing in order to reach the essence of phenomena, qualitative approach though uses the researcher as a catalyst of ideas and insights. Morse (1999) argued that qualitative researchers should add to the data acquired in order to present how and what was the study contribution. A qualitative researcher is not expected to be objective but transparency



is required. I have to perform epoché in order to leave the data uncontaminated from my views and experiences, that applies to the whole research process, during the data collection and analysis. Transparency is also required so that the reader sees that bracketing was performed.

It is useful to have in mind what Husserl proposed in order to be able to make the appropriate choice regarding data analysis for a study that follows the Husserlian approach. Porter (1998) mentioned the steps of the Husserlian method for the data analysis, with a reference to the original text:

“explore the diversity of one’s consciousness; reflect on experiences; choose an experience to study; develop a phenomenologic framework; specify a research question; bracket or perform the phenomenologic reduction; explore the participants’ life world; intuit the structures through descriptive analysis; perform the eidetic reduction; create a taxonomy for the context of experience (intention, component phenomenon, phenomenon); create a taxonomy for the context of experience (element, descriptor, and feature); engage in intersubjective dialogue about the phenomena and features (cycle between the first and second formations, integrate the bracketed material into the analysis); determine uses for phenomena and features” (Porter, 1998, p 21).

Spiegelberg (1960) simplified the phenomenological method as a whole into seven steps although he mentioned that only the first three steps were widely accepted by phenomenological researchers and the rest were accepted only by a part of them:

1. Investigating particular phenomena;
2. Investigating general essences;
3. Apprehending essential relationships among essences;
4. Watching modes of appearing;
5. Watching the constitution of phenomena in consciousness;
6. Suspending belief in the existence of phenomena;
7. Interpreting the meaning of phenomena (Spiegelberg, 1960, p 659).

Hallett (1995) pointed out that a researcher may feel that the above orientation in research is not helpful and can result in a search for guideposts. As far as data analysis is concerned, various techniques that are more structured have been developed from others like van Kaam, Giorgi and Colaizzi (Porter, 1998). As Corben

(1999) pointed out, Colaizzi is one of the social researchers who attempted to add structure to the attempt to interpret the meaning of phenomena and this is considered to be derived from the Husserlian tradition of essence and give readers the chance to understand lived experience. Hallett (1995) also cited Colaizzi as one of the psychologists who tried to simplify the phenomenological approach. This systematic approach has been used in a number of nursing studies, for example Forrest (1989), Clarke and Wheeler (1992) and Baillie (1995). As Corben (1999) mentioned, researchers feel that leaving the phenomenon under study unstructured and uninterrupted constitutes a great difficulty and they prefer more structured approaches.

Colaizzi's (Colaizzi, 1978) method of analysis is considered to be appropriate as it provides the opportunity to validate the data by going back to the interviewees. The use of a systematic approach that has been used in a number of nursing studies (for example: Forrest, 1989; Clarke & Wheeler 1992; Baillie, 1996) before was also thought to be important for this study since I was using the method of phenomenology for the first time.

Colaizzi (1978) described the proposed process of data analysis. First, I looked through the participants' interviews to get an idea of them. Twenty three interviews were performed with old persons aged 65 to 91 years old. The participants were evenly divided between the four Open Care Centres. More demographic details are not going to be given for confidentiality reasons.

Then, I drew out phrases or sentences that had direct relevance to the phenomenon under investigation. According to Colaizzi this step involves 'extracting significant statements' (Colaizzi, 1978; p59). Here are some examples from a number of interviews, I underlined the significant statement:

Mr R

EK: This experience...how did it make you feel about the nursing staff?

Mr R: I felt really bad. I really wanted to sue them but I couldn't

because I was a sick man and as you can understand I suffered for about a month until it was over.

Mrs Y

'I am just an old woman...I don't want to bother (anyone)....if I am not well (in my health), what am I going to do then...there is no disease 'old age' to die from. They don't tell you and then I don't want to insist...you feel like you are a nuisance...if I am not told how do I know...something to do right for myself.'

Mr F

'If I was in touch with a nurse? No. Not such luxury exists in Greece. What...are we kidding now?

And he goes on...

Because, now IKA also in order to see a doctor...I mean to queue to IKA...ehm, they have been transformed into lists...you call, you know, some phone line and you make an appointment and by this, the appointment can be set for five days, 20 days, one month later or 35 days later that is, I think, the maximum waiting period...Because I have been going to an endocrinologist, and now in order to make an appointment I have to make it that way...So, I gave up going there any more...I am not going there again because you have to call from 7 until 10 past seven and if they answer and if you find this phone not beeping, you might manage to make an appointment. And to tell you the truth...I had managed it, I had an appointment with the endocrinologist but the day I went I made the appointment for 35 days later. The day I went they were on a strike and my appointment was cancelled. And I said, what the hell...it is over. It does not worth it to be involved with all these...Well and the queues have been transformed into lists. E, personally I have the impression that the benefits...the medical benefits for the Greek people instead of improving, unfortunately they get worst.

Mr G

Let me tell you now, I was at hospital and while I was at hospital my wife got very sick also and we couldn't do anything at all for ourselves and we were spending one thousand six hundred euros a month, per month and of course in addition what I spent for the doctors. I got crazy. I had a small pension and it is left...I got sick after so many years...and I have my wife that has to stay in bed. I didn't see anyone to come and knock at my door. I offered forty years of work...Many sacrifices for the family. I have climbed up to ninety metres high without a safety net...They say 'you have to take all the medication', pay the bills, pay for care assistants. When I was at hospital I had three. I was paying one hundred and thirty two

euros per day.

The next step would be to reveal the essence of each significant statement. According to Colaizzi (1978) this step involves 'formulating meanings' (Colaizzi, 1978, p59).

**Formulated meanings from the preceding significant statements:**

Feeling upset but unable to react due to being sick

Feeling upset for being unable to participate in care due to lack of information giving

Abandon the attempt to use the NHS services as it is considered pointless.

Feeling very upset that the NHS is not able to cover his needs and he is in the unavoidable position to pay to cover the inadequacies of the system.

The above process was repeated for each of the interviews (in this case) and the formulated meanings were categorized into 'clusters of themes' (Colaizzi, 1978; p 59). This is done in two stages: first I referred back to the data collected to confirm the developed themes. Then, I looked for contradictions among or between the various groups of themes and took them into consideration also, discrepant cases were also included in the analysis. Colaizzi (1978) suggested that what cannot be logically interpreted might be the case in reality.

**Themes deriving from the above formulated meanings:**

(Consequences of participation) Participation and frustration with the NHS

The above are used in order to form an 'exhaustive description' (Colaizzi, 1978) of the phenomenon under study. This description should be as unambiguous and straightforward as possible. The last stage of the process is the validation of the analysis by revisiting the data analysis results of the previous steps by the participants. This can be done in one or more interviews, if required and if new data appear they should be integrated into the last product of the study.

This posed a difficulty in the design of this study as when I asked the participants to interview them again, they were hesitant. Most of them answered that they could not



make arrangements for something that would happen three months later. I took into consideration the alternative as outlined by Hantikainen and Käppeli (2000). Although they used Colaizzi's method of data analysis, they returned only to three of the participants for a second interview for validation. I decided that if all the participants would not be willing to participate in the second interview then I would go back only to the ones that were willing to participate.

In this case, I faced a methodological drawback and I did not want to compromise the quality of my data. In the recruitment period the majority of the participants reported that they were very apprehensive about being tape recorded. As discussed above, after careful thought and consideration I decided to ask them to be interviewed for the second time without being tape recorded but instead keep notes. If that failed then only those that would agree to see me would be interviewed. The absence of the tape recorder made all the difference. The participants were happy to see me and participate in the last step of my data analysis.

While searching the literature for research using Colaizzi's method, a number of recent studies that were presenting how the method was implemented: Päävilainen & Astendt-Kurki (1997), Larrabee et al (1998), Fater & Mullaney (2000), Glaze (2001) and Harms & Benson (2003). Päävilainen & Astendt-Kurki (1997) presented their four step method of data analysis in a table, using the subtitles: significant statement, formulated meaning, cluster of themes and finally the main theme. The first impression was that this was a more compact presentation of Colaizzi's method which makes it more manageable as when interviews are used for data collection the amount of data that is gathered can be difficult to manage. Päävilainen & Astendt-Kurki's (1997) terms for the subtitles derive directly from Colaizzi's description of his method (1978) and the use of tables is also found in his description of his method. Thus, I chose to use their paradigm in the analysis of the pilot interviews thinking that the compact presentation of the findings would allow me a better management of data analysis.

However, although Päävilainen & Astendt-Kurki (1997) said that they were using

Colaizzi's method of data analysis, they did not say that they had modified it. Thus it lacked methodological clarity. In addition, I found it more difficult to develop my analysis using their approach. After careful thought and consideration I decided not to continue using this method and instead analyze data with Colaizzi's method as he described it himself.

The interviews would be conducted in Greek; therefore, the analysis would be in Greek. The English translation would be checked by a bilingual professional translator to avoid misinterpretations. The issue of translation was further explored in the section regarding rigour (see p 104-106).

### **Validating the findings**

As explained the last stage of the data analysis process is the validation of the analysis by revisiting the results of the previous steps by the participants. This can be done in one or more interviews, if required (Colaizzi, 1978). A second set of interviews (verification interviews) was performed approximately three months after the first ones in order to validate the data analysis. The second interview was performed without the use of a tape recorder but instead the participants were presented with a summary of the findings (themes and clusters of themes) and I kept notes regarding the points that they agreed or disagreed with. Each copy was coded and filed in the same way as the rest of the data. In general, the verification interviews yielded the same results as the first. Verification was supported by additional illustrations of the verified data. In the presentation of the findings aspects of these interviews that worth mentioning are integrated into the analysis.

There was a slight variance regarding fatalism as a way of living that involves accepting life as it comes was an issue that initially I included in my themes but then omitted in the second set of interviews. In the second interviews, all of the interviewees argued that this attitude was definitely not representative of their attitude towards life. Because this study seeks to represent the participants' views as accurately as possible, I felt I had to omit the term even though it had appeared relevant to me.

In the verification interviews, I found the way they reacted to my referral to fatalism very interesting and I would explore it more if I did not have time constraints. They did not accept the term fatalism and some preferred to characterize their view of the world as realism. Each one of them said that maybe others had shown a fatalistic attitude but not themselves. The general feeling was that they considered themselves as people who try hard to improve their lives. There were some participants who were annoyed by the idea that they could be viewed as fatalists when the findings would be reported.

In addition, the informal character of the interview and the absence of the tape recorder made the participants less conscious of the interview and able to express themselves in a more relaxed and free manner. The fact that the interviewer was now a person known to them also made a difference as well as the fact that the subject matter was also familiar to them and they had the opportunity to discuss again (without being conscious of the tape recorder).

It is also known (Gordon, 1999; Holliday, 2002) that interviewees will not necessarily say the things that are in their mind, either because they do not want to, or because they cannot express themselves as they would like to, or because they do not want to admit the truth. I think that the verification interviews helped respondents realize that others felt like them and liberated them to talk about the issues that concerned them. In addition, as Gordon (1999) pointed out, words and actions do not have the same meaning for everyone. Therefore, my interpretation was tested as the respondents were readers and respondents at the same time. The way they felt about the use of the term fatalist was characteristic of this.

### **3.22 Computerised versus manual data analysis techniques**

Another issue that was identified while searching the literature was the use of computerized methods for data analysis. Webb (1999) pointed out that a variety of

software packages have been developed in order to assist qualitative analysis. A brief search on the internet search engine Google, gave me an insight not only of the software packages that were available, but also the prices and the amount of time that had to be spent in order to learn to use each one satisfactorily. I considered using computer packages an inefficient use of time and money. I could not spend the necessary amount of time to buy it and then pay for the course and spend time learning to use it.

Webb (1999) also compared the computerized with the manual technique and argued that inexperienced researchers would benefit from the use of the manual method as it would help them develop their insight in the data analysis. The computerized methods are accused of alienating researchers from their data and making coding appear as a mechanistic process (Webb, 1999; Morrison & Moir, 1998). In addition, in the literature, phenomenological researchers do not appear to have used computerized data analysis, which means that this method had not been tested for use with this theoretical approach. Using Colaizzi's data analysis method poses another difficulty as the extraction of significant statements is very demanding and software packages are not suitable for all methods (Webb, 1999).

In conclusion, I judged Colaizzi's method to be the most appropriate method to analyze the data, as it is the most structured one and it also gives the researcher the opportunity to validate the findings. It is a method that has been successfully used in many nursing research studies and suited this study.

### **3.23 Limitations of the research design**

Qualitative researchers study people's perceptions and reports or accounts of situations and events. These reports may be unreliable, biased, or contradict other reports. In addition, the amount and the quality of data and the depth of the analysis are dependent upon the ability of the researcher. A further complication is mentioned



by Bowling (2000), who argued that researchers are part of the cultural, social and political context of their work. That can be a strong or a weak point of the study, depending on how clearly the researcher distinguishes personal interpretations from the rest of the text.

As mentioned earlier, bracketing is difficult to practise and I myself as the researcher can represent a limitation. I realised that I could not forget what I knew but I could make an effort to keep myself under control and not interfere with the process of data collection and data analysis. Parahoo (1997) argued that in interviewing it is difficult for the interviewer not to influence the interviewee, and that sometimes this can occur without the interviewer realising it.

Performing the interviews while performing phenomenology according to Husserl, was a very challenging and often stressful process. I was a novice researcher that did not have considerable experience in interviewing and often I was feeling the need of going back to the literature see if others faced similar problems, how did they manage to overcome them and then try again. This made me feel that interviewing is a craft and not a process that can be fully controlled. It is used for research purposes and there is an appropriate way of performing interviews.

The interactive character of phenomenology can prove to be one of the weak points of the method. My objectivity is questioned because of the personal involvement and the fact that the researcher is a tool of data collection and analysis. The interaction process that takes place while a researcher investigates a phenomenon is unique and cannot be reproduced by any other researcher (Parahoo, 1997). It is apparent that at a different time, or if a different person was performing the analysis different themes could be developed. The question though is if this would also lead in presenting a different meaning for participation.

Another point that needs to be raised is the issue of saturation. Although when I designed the study I thought that I should keep interviewing until I reached saturation (which means that I would reach a point that no new themes would be found) I came

to realise that I had to take other factors into consideration such as the time and money limitations and stop the interviews when I actually felt ready to write the theses. In addition, hypothetically the probability is that some interviews might look alike, you think that saturation is reached and then suddenly new themes might appear, thus someone can never be certain that saturation is possible.

I performed twenty three interviews for this study, after the eighteenth interview I started feeling that I was listening to similar stories. I continued interviewing and this feeling was becoming stronger. When I reached the twenty first I decided that I would go on and perform two more interviews that I had already arranged and if I continued having the same feeling I would finish data collection. Although, my concern was that perfect saturation might not be feasible I had to take into consideration other factors such as time limitations, as well as be realistic as the whole population cannot be interviewed and stop the interviews when I felt that I was ready to perform the analysis and write the theses. As Bowen (2008) points out there are no guidelines on how to reach perfect saturation and in many papers there is no discussion on what they mean with saturation.

This research was funded by a governmental funding body and the issues of cost were important in the formulation of the research design. That put some constraints on the decisions that had to be made about the research design. Another limitation was time as the timetable of the research had to fit the PhD time limitations (University of Edinburgh, 2001), according to which the time spent in Greece could not exceed 15 months in total.

Another limitation is the issue of language (see also p. 26). This study was performed in Greek, therefore the analysis was also performed in Greek. However, the results must also be reported in English as this is a PhD study. It was stated earlier that communicating research that goes through a process of translation is an issue of concern especially in qualitative research. In this case I needed to translate not only the results of my research but also the supporting quotations from my first language into a second one as accurately as possible. I needed to read a lot and gain valuable

knowledge on translation and the sensitivity of data when they undergo such processes. Bearing these issues in mind, the advice of an experienced bilingual translator was thought necessary which increased the cost of the performed study.

### **3.24 Summary**

This chapter has described the research process of this project which explores the issue of how old persons perceive participation in nursing care, while living in the community. The phenomenological perspective was chosen because it offers a fresh look at the phenomenon and focuses on the investigation of the meaning of phenomena. Phenomenology, as a qualitative method, studies individuals' experiences and perceptions in their environment (Anderson, 1991; Holloway & Wheeler, 1996; Morse & Field, 1996).

Phenomenology, as a method, has various approaches that were explored and it was considered that Husserl's approach suited best the purpose of the study as a more structured approach was preferred for the analysis of the data. Colaizzi's method was preferred, as it is a well constructed and tested method which advocates returning to participants to verify the data. The pilot study gave me the opportunity to improve my interviewing technique, tackle the issue of translation as the interviews and the analysis were to be conducted in Greek.

A detailed report of the research process was presented in this chapter to explore the widespread critique regarding the application of the Husserlian perspective of phenomenology. This chapter was intended to give the reader an analytic account of the process so that it is possible to evaluate this study. In this chapter, I have also explained what approaches to ensuring rigour I took into consideration when implementing this qualitative study and informed the reader of the criteria that were used. It is evident in the literature that qualitative research has long since left behind the use of quantitative criteria, now using criteria that have been developed particularly for qualitative studies.

According to Hallett (1995), the value of phenomenology lay in the fact that it focuses on the participants' perceptions and gives the researcher the opportunity to gain an in-depth account of the researched phenomena. According to the Husserlian approach, phenomena are studied as they appear through consciousness, and experience is considered as the ultimate ground and meaning of knowledge (Cohen, 1987; Koch, 1995, Walters, 1995).

Jasper (1994) commented that the focus of phenomenology, the clients' experiences, can be used to plan future care because it is the clients' needs that can be identified. Therefore, the results of a phenomenological research can contribute to the provision and the evidence base for high quality care. So although phenomenology poses some challenges to the researchers that use it, it not only serves the aim of the study, but also has considerable advantages to nursing practice in general. Ashworth et al (1992) stated that if patient participation is going to guide caring practice for nurses then there is a need to unfold its essence. They suggested that phenomenology as a method can at least provide carers with the understanding of what participation means to the participants.



## **CHAPTER 4**

### **REVEALING PARTICIPATION**

#### **4.1 Introduction**

In the previous chapters I gave an overview of the Greek health care system, clarified issues on terminology, and presented my literature review, the theoretical framework and the research process of my study. In this chapter I will present participation in nursing care as viewed by the participants of the present study. As I have already explained in the data analysis section, I used the data analysis method that was developed by Colaizzi (1978) and as presented in the relevant section ( see p 157-164).

The data analysis has been a long process. The aim of data analysis is to analyse the data as well as possible, but data analysis can be an infinite process. The process of data analysis was under constant revision and improvements as a result of achieving a greater understanding of the analysis process, as well as the phenomenon under investigation. After performing part of the data analysis I felt that I needed to take some time off and return to the data analysis with a fresh mind. Taking some time off helped me think more deeply and look clearer into my data.

In this chapter I will explore my the product of the study, including the relevant quotations. For confidentiality reasons I will not refer to the dates or the Open Care Centres from which the interviewees were recruited from in the quotations I will include in the following passages.

## **4.2 An overview of the findings**

What was apparent in the interviews is that participation is characterized by fluidity (by fluidity is meant the changeableness, variability and flexibility that can be encountered in a situation). Fluidity is apparent in each one of the participants' accounts. The themes and the clusters of themes that emerged were the outline of the findings account. It was apparent from this study that participation was experienced with an astonishing diversity. People experienced participation in a variety of settings, in hospital and the community. Their experiences involved members of their families as well as their friends, neighbours and members of their communities, forming a circle of support.

Respondents felt that participated in nursing care at their own home, at the hospital, at other persons' homes and at the open care centre. They involved themselves, parents, parents-in-law, husband or wife, friends and peers and performed: medication delivery, measurement of blood pressure, measurement of blood sugar, personal hygiene, feeding, trauma changes, catheter bag changes, subcutaneous and intra muscular injections, maintaining comfort, reassurance of the patient, communication and co-operation with the doctor. The extent of participation varies depending on personal ability, willingness, resources, support from the services and environment. Helping neighbours and friends, supporting other members of the Open Care Centre were also included.

The reasons for participation in nursing care varied as well. There were personal issues such as the financial burden, the political orientation, feelings of reward and taking control of their lives. Others included feelings of distrust in the NHS and health professionals, disappointment in the care provided by the NHS and the quality of care provided by doctors and nurses, the power relations in health care as viewed by the participants: among doctors and nurses, patients and doctors, patients and nurses. Furthermore, there were matters grounded in societal, political, moral and

religious beliefs widely accepted by the society, forming a circle of support or on the other hand feeling let down by society: generations that were involved in major historical events, who contributed to the development of the NHS do not feel that their contributions are valued by society.

Participation is crystal clear that entails considerable advantages but it has also to be pointed out that disadvantages have also been mentioned in the interviews. Effects of participation in nursing care for old persons are both negative and positive. Negative factors include the personal burden, attachment to the carer, adjustment to a new, more deteriorated, way of life; the financial burden; the emotional and physical fatigue and anxiety. On the other hand there are positive outcomes such as a sense of personal development from the experience, satisfaction, emotional and spiritual reward, a greater ability to meet the patient's needs, security, control, empowerment, feelings of independence (being able to rely on themselves for their care), fulfilment of their role in society (doing their best for their family), achievement, appraisal from the family and the community and gratitude.

The overall feeling I acquired, when I finished the interviews and read them again, was that participation is a phenomenon of extraordinary diversity. It became clear from the interviews that the phenomenon manifests itself with a great deal of fluidity. Although the participants were asked about participation in the community, each one of them described the concept within a different setting, involving different individuals as participants, performing a variety of tasks, each at different levels, as well as making decisions and taking initiatives regarding their nursing care and treatment. They even evaluated their care provided by the National Health Care System. In addition, the themes that emerged were presented by each of the participants from a diverse viewpoint. What was described as an outcome from one person could be viewed as the motivation for participation from another.

The significance of participation for the participants was obvious by their willingness to talk about it and remain focused on it. However, some participants did not appear to attach great value to it: the conversation led to other issues considered to be of

major importance for the participant. For some participants it was more important to talk about other issues of concern: this group were more willing to talk about issues concerning family, personal achievements, hobbies and historical events in which they had participated. Yet, most participants, did seem to find it important enough to talk about.

### **4.3 Unfolding participation**

#### **Participation an unlimited resource of care**

Participation as a phenomenon is characterized by the variety of the persons involved, settings and levels of participation. This varied meaning of participation was described by all of the participants in my study. Although they were asked specifically about their views and experiences regarding participation in nursing care in the community, they did not focus their accounts only on themselves or their homes. When I first came across it in an interview I was surprised and thought that the participant did not understand the question. I was tempted to interrupt the participant and ask to focus on herself. Instead, I thought that I should use *epoché* and let the participant talk about what she thought was relevant and not contaminate the data with my preconceptions. I remained concerned, however, that the answers would be irrelevant to the topic. When I performed the next interview I was not surprised that the next participant was also talking about family and I started realising that this meant something for the meaning of participation.

By the end of the interviews I had realised that they rather viewed participation as a continuum of care that covered all settings and involved their families, friends and peers. The level of participation depended, varied according to the individual's capability, likes and dislikes, or necessities.

As far as the persons involved, are concerned, they can be presented with a pyramid (figure 1, p 282). The base of the pyramid, is more inclusive and is consisted of the



friends and peers of each person. Participation is an act that involves the community as a whole. Community participates in caring for its community members and basic health care needs are covered. Even if a person does not have a family, friends and peers as well as the extended community could be involved in caring. Thus the community can be considered as the base of participation.

The second level of the pyramid involves the family, and is more selective. Family participates in the care of siblings, children, parents, parents in law, husbands and spouses. It is not as wide and inclusive as the community but its involvement is closer and it undertakes more tasks as well as for a longer time span. Family is there for the person who needs them and ready to undertake any task that would make things better for the one in need. The participation is under fewer restrictions. Family participation in nursing care is a significant contribution in caring.

On the top of the pyramid is the person itself. A person is the focal point of participation. Persons will take part in their own care, be part of the family and the community as well as the nursing care for family members and community members. A person is interviewed and will give a personal perspective of the issue under investigation. It needs to be noted that this study is based on personal accounts as well as investigates these personal experiences. It is the person that all these accounts start from and end to.

As far as the setting was concerned, while participants were asked the same opening question that clarified that community was the setting under investigation, there was a variety of answers (figure 2, p 283). All of the participants reported home to be the primary site where participation occurred. As this study was focused on the community it was an answer that raised no questions. As the interviews progressed, it became apparent that participants saw participation in a continuum and they would refer to their experiences from other settings as well, such as hospitals.

When participants explained what participation meant for them, they referred to the delegation and performance of tasks, decision-making, or even the creation of choices as actions of participation (figure 3, p 284).

An aspect of the phenomenon is caring for friends and peers in the community, people taking care of their neighbours, friends and peers. There were cases where people took the initiative to offer psychological support to people that needed it, organizing groups in order to achieve that.

Mrs A was very explicit in her description of what is participation in nursing care for her. Mrs A, viewed participation as an activity that was part of her routine, a necessary alteration to her way of living that would be on a long term basis:

‘I know that I can do more than sitting and waiting for someone to take care of me. This is my home and I want to be able to stay here and be independent, caring for myself. This is what participation means to me, doing things for myself, in my own home. Life changes and my everyday routine changes as well. Now that I grow older I have to take care of my health...we are not going to get any younger...Someone needs to show us new things and we have to do them as a routine.’

There are also those who view participation as an everyday fact of their daily lives. Mr T saw participation in nursing care as a part of his life that should be treated as such. Participation in nursing care was seen as an activity that should be organized in everyday life as any other. He felt that it was not necessary for nursing care in the community to be given by professionals, and that it should become part of people’s everyday lives so that they could maintain control over their health care. Mr T said:

‘You know I want to organise my own programme and do things when and as I wish. I am set in my ways and I cannot just be told to do that and the other thing or just wait to have something done. I can do things better myself. This is how I am. Why should it be any different now... I wonder... I always took care of myself.’

‘I wake up in the morning and start my day. Once it was about going to work and then being with my children. Now it is about taking care

of myself. Taking my pills, going to the physiotherapist...one needs to have a schedule.'

Mr F attempted to summarize his participation in nursing care as the things he did to maintain his health at home, without any referral to participation in the management of illness:

'Of course when somebody has problems he is obliged to monitor his condition. If he wants to live a few more years. Eh...I, on my own, measure my blood pressure and on my own I measure my blood sugar. In the past I had been measuring my blood sugar on a daily basis. Now, once a week, and I have regular communication with cardiologists. That's all...'

Furthermore, it was revealed that participation could be initiated and implemented without any advice from health care practitioners. For example, when asked for more details about the measurement of his blood sugar levels, Mr F pointed out that participation can be motivated on a personal level that is rooted in the information obtained regarding not only health issues but also modern developments in monitoring health:

'Ehm...it was on my own initiative. When I heard lots of years ago that there is this possibility, because I started measuring my blood sugar ten years ago. When the machines first came out and I was interested, I went to a pharmacy and I asked if they exist...It existed...I bought it...I read the instructions and I used it. Nobody has shown me (how to do it).'

Participation in nursing care may be performed even if health professionals advise otherwise. Mrs I was one of the participants that admitted that doctors and nurses had suggested that she should take some time to rest but she would rather stay with her loved ones. She also reported participation in nursing care in both the community and the hospital. Mrs I also focused on the care that she provided for her mother:

'She was alone at home, I was giving her medication. At hospital, in the unit I was changing her, looking after her...feeding her, whatever I could do...To tell you the truth the doctor was telling me to leave the hospital and the unit, he was saying 'go, and your mother is not

going to die’.

Mrs D was a participant that took care of her mother-in-law, her father and recently her husband. Participation in nursing care was a part of her everyday life and started participating in nursing care as a matter of necessity:

‘The injections...the doctor...my mother-in-law got sick. God bless her, and I say...he says that she has to do injections. ‘Who is going to do the injections?’ ‘You!’ he says. And the doctor showed me and from there on I got used to it and ...not only for my mother-in-law but for others that were [sick] too. My father became sick too. [I cared] For everyone and all the time.’

A little later in the same interview Mrs D let me know that her husband was sick as well:

EK: You take care of your husband too?

Mrs D: I am always taking care of someone.

More interviewees pointed out that they participated in nursing care in other settings than their home, or even the community in general. Mrs O pointed out that she also took care of her husband when he was in need, but in this case in the hospital setting. She also stated that her care of her husband was not focused on certain aspects but rather included everything, at least as far as she could think of. She stated:

‘Some time ago my husband was in hospital as he had broken his hip and I was there every day and I was taking care of him in every aspect.’

The same participant, Mrs O, also made a point of the fact that a continuum in care is experienced. She presented it as a necessity. Caring had to be constant and it was not contained within one environment:

‘I just had to do it...because he had been in hospital and then came back home and...the circumstances were difficult for anyone else to help...so the doctor told me ‘do that’ and I was taking care of him.’



When asked about participation, Mrs W focused her interview on the care that she provided to her husband, at home. Thus she focused her story on experiences that were in the community but also involved caring for another person. This activity involved basic nursing care and giving medication as well:

‘Of course, I was giving him his medication, I was undressing him and I was bathing him. At the end he could not even go into the bath and I had this plastic on his bed like the women after giving birth...I was bathing him, taking care of him, that’s all...’

Another aspect of participation in nursing care is caring for the old at home. The participants in this study mentioned that caring for the old at home was preferable. Nursing homes were not seen as very appealing and the provision of care to the old at home was presented the only option participants would consider, unless there were extenuating circumstances.

These views were quite strongly expressed, but they were only expressed after the tape recording ended. Participants were quite concerned by what would happen when they would not be able to take care of themselves. I realised that having lived in a family that my grand-parents were living with us, I never thought of whether things could be different, or the concerns and difficulties that could be attached to it. I was quite surprised though that nursing homes were viewed in such a negative way.

Mrs D was one of the few to bring the issue up whilst she was being recorded. When asked if she would take care of her father if there was another option available to her, she answered a definite no as she thought that she was physically fit enough to do so:

‘No, no. Then I was able to (care for my father)...because so many years have passed by and I was younger and I was able to take care of him...on my own.’

In addition, Mrs B said that she would never consider the option of a nursing home for her parents and she expressed very strong feelings against them:

‘Not everyone wants the old in their homes. They say they are demanding and they can’t stay with them all day to take care of them. They have to work. They say that they do not have enough room. I know that if you want you can fit everybody in your home. I don’t know how they can separate themselves from their parents and put them in nursing homes. They send them somewhere to die. They should try going there themselves.’

## **Participation as a social phenomenon**

Participation in nursing care was viewed in relation to society. Participants mentioned that in communities there is a circle of support that starts with close family and extends to friends, neighbours and peers. They form a network of support that interacts with the health care system and health care workers and society as a whole.

Furthermore, Mrs A told me about an initiative that was started by a group of members of the Open Care Centre to visit people who were lonely and too frail to go out:

‘Yesterday, I and a couple of other women went to see X. We decided that we should go and give her some moral support. Being alone almost all day and not talking with people...Very sad. It can drive you crazy...But what else can we do? We said let’s go and see her, once a week.’

In other cases participation in nursing care can be in the form of offering expertise to the extended community, which can then take advantage of it in order to meet its health needs. Mrs D, had learnt some skills such as giving injections and she stated that since then she had helped others until her health deteriorated further:

‘Although I have given a lot of... injections to many people. And they still prefer me, they ask for me and I avoid it.’

The verification interviews reinforced my initial interpretation. In verification interviews, participants stressed their feelings about having been let down by society. They felt that they had worked hard in life and now that they were no longer able to fight, they were left alone with their problems, without support. Participants told stories from the battles that they went through to emphasize their opinions.

The relationship between the community and each participant seemed to be beneficial and based on grounds of mutual trust and companionship. The issue of a cycle of support is existent (people help others knowing that they are also going to get help in return at some other point). Mrs K pointed out the following:

‘Now, I am going to my friend and helping her, tomorrow someone else is going to do the same. People pass by to see if I am all right if they do not see me for a while. I do the same for them. We take care of each other. If something happens I trust them that they will do their best to help out. Sometimes we tell each other our problems and...we take them off our chests. It helps to know that there is somebody to listen to you when you want them to. If we were not like that, I would be totally alone now. She (friend) fell and broke her hip and...and we passed by and she did not answer and we called her family and they took her to the hospital. Imagine if nobody had come around. Life is difficult for people to live on their own.’

Some expressed concern about reactions from the community as they felt that they had had hard lives and ought to be offered something in return by society. I was actually taken aback by a participant, Mr G felt that neither the community nor the family were giving back anything to him despite his sacrifices:

‘I didn’t see anyone come and knock at my door. I worked for forty years ...Many sacrifices for the family.’

What he said had nothing to do with being a good neighbour or forming a circle of support, not even duty and solidarity with family. It was about dealing with isolation and an unsupportive NHS.

Moreover, Mrs W pointed out that historically they belonged to a generation that had suffered:

‘We are people that have suffered a lot. We had the war when we were children. We got married, we got our men. The best, the nicest thing is that we had nice children and nice grand children.’

As I was listening to her memories by my late grand parents flashed back in my memory. It was like yesterday that I was listening to my grand parents talking about the Great War and being proud of the way their children and grand children turned out. I was really moved by this interview. When I finished it I heard it again, so that I can perform epoché and not contaminate the data analysis by reading too much into it as she reminded me of my grandparents.

The feeling of belonging to a generation that went through difficulties due to historical events was verified by all of the participants in the second set of the interviews. It is further explored in the relevant section.

Participants of this study referred quite often to a past that shaped their present and was expected to influence their future. They talked about challenging conditions in their lives that were a result of major events such as wars and political unrest. They even talked about the way they had been raised by people that had also lived under difficult circumstances created by major events. They also expressed the view that they expected more from the present and didn’t believe that the future would bring better conditions for them. Briefly, they viewed participation in nursing care as a consequence of historical events that had taken their course over years. As children they had the memories of stories told by their parents and their grandparents about wars and social struggle and as adults they lived their own stories of war and unrest.

One of the participants, Mr E, described his feelings in detail. When asked about when he thought had been the first time he participated in nursing care, he gave the following answer:

‘Once, I knew that I had nowhere to turn to...it was all about doing as much as one could. Our parents were very tired...People that suffered a lot. We knew that we had to do as much as we could to



help them, since we were children and...this is how we grew up. First came the Germans and the Italians and then the Civil War...and then the dictator. I wonder how we managed (our everyday lives). Now, I still sometimes think that I will wake up and it (war) will happen again. Then, I think it is over...but still it is in the back of my mind. You know it is the feeling that you have nowhere to turn to except your own people. You have to be close and take good care of them and...hopefully, you might not need any help. You know, it is not the feeling that you have to be like that or that you do it to get something in return...you take care of them because you want them to be well and have them by your side...you don't want to lose them and be alone in such a harsh world.'

He continued:

'We had a difficult life and we could understand what our parents and grandparents had gone through. It is one thing to listen to facts and another thing to actually live them. You are so young...you weren't even born when we had a dictator, were you? You can't possibly imagine what others went through...It is not that young people don't want to, but how could you? Even I couldn't feel how my parents felt when they left our house in Smyrna and lost family there...and they came here to start again, having nothing but a name. They told me that life is difficult and what is to be salvaged in moments of despair is family, lives...that's all.'

Another participant, Mrs M, pointed out that they belonged to a generation that had been through war, like the previous one, and although they had fought with the expectation of a better and easier future, they now felt forgotten and that their expectations were not being met:

'Yes, we went through a lot and we had greater expectations from society...we fought to maintain our freedom and build this state...now that everything is peaceful we expected an easier life. Our parents had an even more difficult life than us and we took good care of them...we stayed by their side and made their last years easier. They did the same thing for their parents and they did the same for their grand-parents. They recognized the fact that they had fought against the Ottomans and given them a state to live free. We fought as well but now it is forgotten...I think that no one looks back to realize what happened then...'

Mr J, another participant, also talked about the events that had shaped their lives and relationships with their friends, family and the rest of the community in general:

‘I am not sure if things can be the same in the future. We grew up under difficult circumstances. We lived through wars and a dictatorship; we had to fight to make a better future as did our parents and their parents before them. Now you find things easy and I don’t know if you know how to fight for a better (future).’

The above quotations make it apparent that participants traditionally were taught by the previous generations to participate in care, not only their own but also that of their family, friends and any other members of their community. Furthermore, they pointed out that living conditions were considerably different in those times as they could not always count on services to take care of their problems and they had to use their own or community resources. They also felt that younger generations who do not share the same experiences could not understand them or provide services that could meet their needs. They felt that younger generations could try harder to make a better life for them and society in general.

### **Power and control as elements of participation**

Two of the essential experiences that were presented in relation to participation by all of the participants were power and control. Participants welcomed participation as an empowering experience, but each one to a different extent. In addition, issues of power and control formed part of the interviewees’ interactions with health care professionals in relation to participation.

The feeling of control over their lives acquired through participation was a feeling that was shared by the participants. It was manifested in a variety of ways. One of the participants saw participation in nursing care as passing to ‘adulthood’. It was viewed as a valuable change in everyday life. Mr Q presented his views in such a way that made me very aware of my own fears, the truth was that I could not imagine

myself being a nurse, being totally dependent on someone in a hospital setting. I could relate to their fear of losing their autonomy and I felt worried that as I would grow up I would lose my autonomy due to ill health. This study was not about me and I had to focus on the participants and tell myself that this was about them, not me, my future life was not the projection of their narratives.

When reading the interviews to acquire an overall feeling about them I realised that I was drawn to the version of the story as expressed by Mr Q as it had a stronger impact on me. I read the interviews again and again and I managed to detect and set aside my feelings. Thus, the product of the analysis would be pure.

Mr Q said, regarding control:

‘When I first started doing things for myself I felt so independent. It... I felt that at last I could start to be in control of my day again ...you know when you wait for somebody to take care of your problem, it is like what you think a baby feels like. I feel like a grown up again. I might not do anything much but I am doing it. Myself.’

He made me see my interaction with old persons as a nurse with a total new outlook. Cases of old persons that I left waiting while I was doing something else that I thought was more significant, came into my mind. It came as a shock to me that I never realised that what I thought of as insignificant affected them deeply.

However, other participants wished for limited participation in their nursing care. In addition, even though control was recognized as a positive outcome of participation, it was also pointed out that there are certain concerns related to it. Mrs L was one of the participants that summarized this attitude:

‘It is helpful to take care of yourself. I am not going to say that by participating I did not take some control over my life...but how many things can you do on your own. How well are you going to do all these. I think that sometimes I need someone else to tell me what is best and do things for me. I don’t know everything and I do not want to know everything. This is why people go to university. I just feel that I am not so brave.’

Moreover, relying on an expert by the interviewees for complicated or matters that need special attention was also mentioned. Otherwise, they are not happy to give up their nursing care. Participants categorized the nursing interventions in their own way that expresses their ability to participate or in other cases how demanding they are.

Mr R pointed out that participating in nursing care makes life easier but there is the need for a specialist to be involved on occasions when care is more demanding.

EK: Do you prefer taking care of this on your own or you would rather have a professional nurse that would come to your home for this?

Mr R: Ehm...for things that are simple and you can do on your own it is better to do them on your own in order to avoid queuing. But there are other things that it is beneficial to have a specialist check more often.

It became evident in the interviews that information-giving was considered essential in order for participation to be performed. Patients reported that they felt comfortable to make a decision and participate in care only when they were given adequate information. However, participants stated that information-giving and the attitude of professionals towards this were disappointing. They did not feel that the information they had received had been adequate to allow them to participate fully in their care. These were issues that I came across in both my practise and the literature, but yet very interesting to see how these were experienced by the participants, thus approach these with a fresh mind.

Mrs A expressed her concerns over the ability to participate if someone is not given adequate information:

‘Yes, I want to be a part of everything that has to do with my health...but how. I am not an expert, I cannot see well to read and I don’t know how to use these computer things. I am left with the television. I don’t expect doctors and nurses to tell me much...not any more. I cannot keep asking if they are not going to pay any attention. If



they don't tell me what and why I will do as they say. Sometimes I don't even know what my medication is for.'

Mrs N offered an example of an occasion when participating in her husband's care was a result of her feeling that she could cause trouble for herself if she asked for more attention by the staff:

'What else is there to do...you see that nurses are not there when you need something, you see that your husband is not as clean as you would like him to be, what are you going to do? Once I asked them to change the bed. They did not come. I went and asked why. They gave me a pair of clean sheets and told me that if I want I can try to do it as they had other priorities. Yes, I did it. It is not that I want people to serve me all the time, I want to do things on my own. I don't like to wait but even if I did not I would not have any other option. Would I?'

It was evident in her facial expression, the tone of her voice and her body posture that she felt very strongly about it.

Interviewees expressed the view that information-giving was poor as a consequence of time limitations in their interactions with staff. When asked if he was given the information he felt he needed, Mr R answered:

'No, because they were always in a hurry, both the doctors and the nursing staff and you were always told few things and you were always left with questions that were not answered.'

In the present study participants expressed their experiences of their interactions with nurses and made it clear that they felt that by having information, nurses exercised control over them.

Mrs A pointed out that information-giving can be difficult among participants and nurses:

'Yes...I thought I would ask...I waited and waited...nobody would let me know what and how I would do at home. Finally I asked and asked and they never had time. They would answer in two words. I insisted

but...only that last nurse sat down with me for ten minutes to let me know what would happen next.'

Mrs A raised another aspect of her interactions with nurses when she tried to let them know that she wanted to participate and be prepared in order to be able to do things on her own:

'They looked at me and I kind of thought that I am back at school giving the wrong answer or making the wrong comment in the classroom. I kind of expected to be shown my place'.

In addition, it was obvious in the study that participation was experienced differently in different environments (both the place and people involved). The interaction with health care professionals differentiated according to the setting. Hospital was viewed as a disempowering environment in comparison to their own homes.

Mr V expressed strongly his opinion regarding hospitals:

'As soon as you enter the door you feel sick. It is the smell, the noise...It is that you are told what to do and where to go and when to sleep and what to eat and drink. Let alone that you cannot come and go as you wish. You eat hospital food, sleep in the hospital bed, live with your hospital mates and do as the hospital staff tell you. I just want to escape. I just want to go home and see no more uniforms. At home I know that I do what I want, I sleep in my bed. There is nothing better than that.'

On the other hand, this study which was conducted in the community revealed the existence of a different power balance in comparison to the hospital setting. Participants discussed the feeling of control over interactions with health care professionals when these were performed outside the hospital and more specifically in their own homes. Mrs A mentioned that she felt that there was a difference in the relationship with health care professionals in the community:

'Being at home...well, I prefer having care at home. Because they come to your home they show more respect. They listen to you more. You are the hostess and...they are not at their place. I am at home and I feel comfortable and they come to see me.'

I could not help but wonder whether our interaction would be different as well if the interview was taking place at the Open Care Centre. I could see that she was not just my interviewee, she was my hostess which obviously made her feel in control.

Another issue that emerged but not during the time I was recording the interviews was the issue of power among doctors and nurses. This is a significant issue as the relationships among health professionals and people's perceptions about them can influence the presentation of the phenomenon under investigation. In this case, doctors were considered to be the most powerful group among health professionals. This issue will be discussed in more detail in the sections regarding the political orientation and the organizational deficiencies of the NHS.

In the verification interviews the issue of power relations in health care was also brought up. Participants referred to nurses as having a subordinate role in health care in relation to the doctors. They thought that nurses were necessary but they considered doctors as more authoritative figures.

Power relations in health care brought forth discussions on the status of the professions. For example, one of the participants thought that I would become a medical doctor after finishing my degree. When I explained that this was not the case, he was astonished by the fact that I spent so many years studying, only to remain a nurse. When I asked why he thought that this was strange, he told me that nursing did not seem to need that much expertise or study and that he could not see how my qualifications would be beneficial for me, as I remained a nurse, with a subordinate role in hospitals, bad working conditions and a relatively poor salary. One of the female participants expressed the opinion that even the uniform with the hat, that some hospitals still have, can be considered degrading for nurses. Participants expressed the opinion that the shortage of nurses was a consequence of this.

It was quite unsettling for me to come across such views. I wanted to know what they thought and see how this is related to participation in nursing care but on the other hand I felt a bit degraded and disappointed. I had the impulse to defend myself as a nurse. However I knew that this was not my role at the moment and I had to set aside such impulses. This study was not about me but about them, thus, I focused on them.

## **Participation as a source of reward**

Participation in nursing care was considered a rewarding experience by the participants. Each one felt that they had been rewarded to a different extent and in variety of ways, but it was a feeling common to all of them. Moreover, reward was viewed both as an outcome and a motivation for old persons to participate in nursing care.

Although participation in nursing care is viewed as a challenging process and participants did not downplay this aspect, the rewarding feelings that they accumulated were stressed as a factor that motivated them to continue participation. Participants expressed the opinion that participation in nursing care was one of the things that gave them the confidence and the will to go on with their lives in general. It is evident that participation is a rewarding experience and old persons are motivated to participate because of that.

Participating in nursing care cannot be viewed as an easy process. It has considerable negative outcomes that participants took into consideration. It was however reported that the feeling of reward that participants gained from this challenging process outweighed the negative outcomes and the difficulties. Thus, participation was viewed as a reward in its own right. Mr C mentioned the following:

‘Sometimes I thought that it was too much. Maybe I should not do all these things and let nurses do what they could. But it does not feel as good. I think that if I did not take anything back I would stop doing things but when I don’t do anything it does not feel as good. I feel



alive and I just think that every time I do something it is a reward in itself to be able to do that. Again and again. Knowing that I can make it one more day and go on makes me more willing to go on'.

Another participant, Mr V, mentioned the following when he was asked about his feelings towards participation:

'As happens with all things there are good days and bad days. Sometimes I feel negative towards it, other times positive. The point is that in order to keep doing something it has to be giving you something back. It is the same in this case. Reward keeps me participating. It is definitely rewarding.'

### **Participation as a source of satisfaction**

It was mentioned earlier that old persons view their participation in nursing care as a rewarding experience. Satisfaction was presented as one of the accumulated rewards to those involved. Mrs O clearly expressed her experience of satisfaction when participating in her husband's nursing care:

EK: I mean how have you been feeling about doing all these things.

Mrs O: Oh, no...I have been feeling...nice, I felt satisfaction. I was doing everything with joy. I was not forced to do anything. Anything, it was done with joy.'

Mrs O also said at a later point of her interview regarding participation in her own nursing care:

'Of course on my own. This is satisfaction...It is something good. Ehm, even injections if it is needed I do it on my own, it's not a big deal...It is that you become more experienced and it is satisfaction that you gain experience to take care of yourself. Yes...[silence].'

It is worth mentioning that satisfaction is one of the characteristics of participation that is both a result of and a motive for participation. It is significant that participants

of this study expressed the feeling that participating in nursing care can be a source of personal satisfaction. They felt satisfied with themselves because they could still succeed and remain active and able to take care of themselves and offer help to others.

### **Participation as the means of gaining the appraisal of significant others**

Another benefit of participation was the positive appraisal by others. This was a benefit of participation in the nursing care of others. Being praised by the loved ones for the care offered was presented as a significant aspect of participation. Appraisal can be presented in a variety of ways.

Mrs W, a devoted wife that took care of her husband for a long period, gave a very emotional account of her experience:

‘And when I was expecting him he gave me his blessing. He told me ‘you have my blessing, I do not have any complaints’. He called our children in and he told them, word by word, exactly as I tell you: ‘take care of your mother like your eyes, take care of your mother like your eyes, she is tired and shattered, if you don’t do what you have to do I will get up and strangle you’. I am telling you exactly what he said.’

Mrs W pointed out that another aspect of appraisal is the avoidance of being criticized by her children if she did not behave appropriately:

‘[he was] Under my supervision...Until the moment I closed his eyes. To have my conscience clean. Not only for my conscience but also to be right towards my husband and my children. Not to have my children tomorrow tell me ‘mother your behaviour was not correct’. I wouldn’t accept that. This is why I believed in it and I did it. Because he was a man who looked after his children, his home, his family. I told you the other thing because you are a grown up girl and you can understand. And even with that...I don’t know if anybody could do what I did...’

Mrs P described her experience of being positively appraised by her mother-in-law, while taking care of her in hospital suffering from a broken leg:

‘I was tired...very tired. She could see it...she would always say something nice. You know, even when I was not very careful and her foot was in pain she would try to hide it and say that I was doing it great. She would always say a nice thing about me, my efforts. Now, that I look back... her nice words gave me the strength to do my best...I was tired and very, very stressed...’

Participants in general were concerned about appraisal which actually motivated them not only to participate in nursing care but also to be very thorough in the tasks they undertook. This is also an element of participation that was not reported in earlier studies.

Appraisal was reported to be viewed through the participants’ personal value systems. Both the person that appraises and the person being appraised share a common value system. They are both benefited, one party by receiving care and the other one by being positively appraised, and thus they are doing something worthwhile that gives meaning to their lives.

### **Participation as a means of gaining gratitude**

The interviewees mentioned that when they participated in somebody’s care in any way, gratitude was one of the outcomes. Taking care of someone and being the recipient of feelings like gratitude can reinforce participation. Gratitude expressed by those that receive care shows that it is a desirable and even noble action.

Mr T stated that:

‘My mother stayed with us until she died. She died calling for my wife. I was her son but still...she was calling for my wife. You see my wife was with her, taking care of her. My mother could see that and

she was grateful for that. She used to say that she was a daughter to her and she gave to her, her blessing all the time.'

Participation in somebody else's nursing care can also be triggered by the gratitude that was felt when being taken care of in a previous situation. Mr H said regarding gratitude:

'I have been sick myself...I know. I want to care for my friend, because I remember when I got sick and my wife was sleeping and waking by my side. I could not thank her enough. It is a sacrifice...She got so tired and...emotionally, maybe more than me. If you say, thank you, it doesn't make anything less tiring for her... I can help others though, because this is what I can do...'

### **Achieving fulfilment of their role in society through participation in nursing care**

Some participants saw participation in nursing care as a fulfilment of their role in society. Based on religious beliefs they considered care of themselves and others as a vital element of their role in life. Participants were guided by Christian concepts such as the Ten Commandments (honouring parents), marriage vows (spouses to care for each other in any circumstances) and the sanctity of the body. Therefore, participating in nursing care proved to one of the ways in which they could reach fulfilment in their lives.

During their interviews they expressed their deep belief in God and His Word. On tape, however, I do not have much evidence regarding the influence of their religious beliefs in participation in nursing care. I think this is due to the fact that religious beliefs are personal issues and the participants probably did not want to expand on them while being tape-recorded.

Participation in nursing care gave the opportunity to the interviewees to act according to their beliefs. Through their actions they gained the feeling that they were living their lives according to their beliefs and goals. In this study participants

expressed their religiousness and made it evident that this was a component of and a strong motive for their participation in nursing care. It was evident that religion held a different significance for each of the participants. The system of beliefs is something very personal and it cannot be generalized. It should also be noted that religion can bring people together as well as divide them. In this case religion and its relation to participation in nursing care will be viewed through the eyes of the participants of the present study.

Participants pointed out that there is a duty in Christianity for married couples to care for each other according to their vows. In addition, participants added that the teachings of Christianity say that children should respect and care for their parents. Furthermore, the opinion was also expressed that helping those in need is an essential duty of a good Christian.

According to Mrs W marriage binds spouses together and they need to care for each other as God advised:

EK: 'Let me ask you a question. A hypothetical question. If you could have somebody else to take care of your husband, would you have somebody else or you would rather do everything on your own?

Mrs W: No, I...I think that every woman has this duty. Since the moment God bonds them, this is how I see it. Now, I don't know how the others see it....'

In addition, there was a strong feeling expressed that it was a sin not to take care of one's body, as this was the 'temple of the soul'. Therefore, participants felt it was essential to undertake all the necessary actions to care for their bodies and maintain their sanctity. There is the strong feeling that it is a sin not to take care of your body as this is the temple of the soul. Therefore, participants think it is essential to undertake all the necessary actions to maintain its sanctity.

Reflecting this, one of the participants, Mr E, said:

'You see, God gave us this body and we have to take care of it.'



The problem that was encountered in representing this issue is that few quotations are available from the tape-recorded interviews. Participants only expressed their strong religious beliefs after the end of the interview and in the verification interviews where they reinforced the already expressed beliefs and stressed their significance.

In the verification interviews, moral and religious beliefs (caring for the family and sharing with those in need) were further illustrated. Participants repeated the view that family was sacred and parents should be respected and taken care of. Paradigms of the Old and New Testament were brought up occasionally as well as anecdotal stories that referred back to ancient times. They all agreed that these were significant beliefs that help communities act with compassion and deal with significant problems. All of the participants felt very strongly about the moral values that were expressed earlier in the interviews as they thought that without these there would be many desperate people in their neighbourhoods.

Participants stated that they were inspired by the Holy Bible to care for others and themselves as well. They did not mention the existence of a bond created in the community based on spirituality or that their faith was reinforced by their problems. They viewed their religion rather as a source of examples of how to live a good life and treat people in an ethical way. In addition, a spiritual community or a priest was not mentioned at all in their interviews. They referred to examples of the Holy Bible but they gave the impression that each one was referring to the examples that they felt personally closest to.

In the same way that religious beliefs do, This study shows that political beliefs as well as politics in general influence the demonstration of participation. Such beliefs operate both as a philosophy that has shaped the NHS and as a personal system of beliefs. It should be noted that not all participants talked about politics in the context of participation. Some of the participants, on the other hand, appeared to be very

preoccupied with politics and they talked extensively about the relation of politics and health care and eventually participation in nursing care.

Mr F, a participant who talked in depth about the political aspect of the issue under investigation, mentioned:

‘Therefore, what I have come to understand is that it is not the system’s fault either, it is about...about a state, with what kind of system it is going to be governed meaning with socialistic, communistic, capitalistic... but it is all about people that are going to be called on to implement the systems. Do you understand? If this is what is important for me...the one that comes and asks for the Greek people’s vote, we will have to see what his intentions are and if he is competent. These are the two. His intentions are...is he going to care for these people, for the people; or his intentions...and if he is able to do. Because often we could have good intentions but are unable, so whether you want it or whether you can’t, it is the same thing.’

Mr F reinforced the above argument:

‘If I was in touch with a nurse? No. Not such luxury exists in Greece. What...are we kidding now? About it...I am not saying much about it. If you don’t pay in Greece no matter how insured you are...you don’t get anything. I mean that everything costs money here. And I have already said that the relationship...between doctors and patients...it is a relationship, I will say it in a blunt way, of a merchant with a customer. Unfortunately...Unfortunately.’

Although none of the participants referred to the above phenomenon when the interview was tape recorded, when the tape recorder was switched off, they all pointed out that this was one of the significant drawbacks of the system. Participants also complained that the national health care system was not free of charge.

In general, in the verification interviews, political beliefs were not presented as an important motive in order to participate in nursing care for most of the participants. Only a small number of participants agreed that their political beliefs initiated their participation in nursing care, but it was not the most significant factor. Although they felt strongly about this and wanted to talk about politics, their concern for their

families and maintaining control over their lives were more important factors for them.

## **Participation as a means of personal development**

Another issue that emerged regarding participation was the idea that participation can be a means of personal development. Old persons appeared interested in gaining expertise and knowledge that would benefit them in the future and be useful for themselves and their peers. As they expressed it, they were eager to become better people by gaining knowledge that would be beneficial. Old persons felt that participation in nursing care helped them gain knowledge on how to manage their health care needs, and was thus an issue of significance in their everyday lives.

Mr S said about participation:

'It is common sense, the more you do the more you learn. The more you learn the better for you. When you are useful to yourself and others the more positive you become about life and you become more willing to live...and live well. It is a good thing especially when you become old and tired of life's difficulties.'

Mrs O mentioned that caring is a source of experience useful for the future:

'Ehm, yes of course. When you take care of a man...and all that, of course you gain experience...you gain experience for your future.'

Mr R said that he felt that participation in nursing care helped in becoming a better person, as he saw it, as it is associated with acquiring expertise and knowledge that is useful in everyday life:

EK: I would like to ask what it means to you, participation in nursing care.

Mr R: It means that I can help myself to become better (as a person). But in order to be able to do so I have to know what I should

do. This is why it is not an easy thing. First of all the patient has to be well informed from a professional. Of course this cannot be done for serious issues but more for simple things.

Another participant, Mr E, saw participation in nursing care as a way of pushing boundaries and achieving personal development by learning new expertise

‘Well, it might...no. Since I started to participate in my nursing care...I told you that I have started using the internet. You know if it was not for that reason I would never have started using it. I got interested because of that other thing, my friend, but then if it was not for me I would not bother to learn how to use it. Now I just use it...and again if it was not for my care I would not be motivated to learn it. It was a good thing that I started it because now I feel that I know something.’

The above mentioned elements also constitute elements of personal development as expressed by the interviewees in this study. It is identified in the present study that participation in nursing care is an on-going process that enhances both care-related skills and the participants’ personalities as a whole. Thus, participation in nursing care needs to be viewed as a complex activity that influences the whole person. It does not only affect somebody’s health but also their personality and its qualities.

In the preceding quotations participants not only related participation in nursing care to their personal development but also stated their awareness of the fact that this relation exists and that they were keen to take advantage of this fact. Thus participation is being moved forward by a new wave of people who are not only active patients but are aware of this status and use this characteristic for their personal development.

Moreover, under certain circumstances, participation in nursing care can be viewed by participants as an achievement. The experience that was reported in this study concerned learning how to use modern technology such as the internet to retrieve information regarding health care.

It is apparent that old persons are not only participating in nursing care but also are able and willing to learn new skills. Both participation and the acquisition of new skills can be a rewarding experience that can contribute to further development of patient participation in the healthcare context. Therefore, arguably, it is vital to offer such opportunities to old persons. It was really interesting to hear that nurses, by facilitating participation in nursing care, could actually affect the person as a whole. I had never thought before that the impact of this would have this degree of magnitude.

Fatalism as a way of living, that involves accepting life as it comes, was an issue that initially I included in my initial themes but then omitted in the verification interviews. In the verification interviews, all of the interviewees argued that this attitude was definitely not representative of their attitude towards life. Because this study seeks to represent the participants' views as accurately as possible, I felt I had to omit the term even though it had appeared relevant to me and explore my initial interpretation.

In the verification interviews, I found the way they reacted to my reference to fatalism very interesting. They did not accept the term fatalism and some preferred to characterize their view of the world as realism. Each one of them said that maybe others had shown a fatalistic attitude but not themselves. The general feeling was that they considered themselves as people who try hard to improve their lives. There were some participants who were annoyed by the idea that they could be viewed as fatalists when the findings would be reported. I thought that they found it disturbing.

### **Participation as a means of personal achievement**

One of the participants took the meaning of participation for him even further and referred to participation as an achievement. He was the only one of the participants that considered participation as such. This is the case as he was taught by his granddaughter to use the internet and retrieve information. Since then he has been using it



to retrieve information for anything which puzzles him and his wife. Mr E told me about it:

‘You know I never liked computers, but once I was talking with my son about a friend of mine that got sick with a disease that I had never heard of and my grand-daughter told me that we can look it up on the internet. In the beginning I thought nonsense...But it was in the back of my mind and then, another day I asked her about something else and she told me and it went on for a while. Then she told me that I can do it on my own. That’s how it started...Now I go and read and then I go to the doctor. I ask nurses to give me things that they’ve never heard of before. I feel the same as when I was at school and started to learn reading and I feel like I really achieved something. It is funny, isn’t it?’

Thus, participation in nursing care can motivate old persons to be involved in activities that can give them the feeling of achievement. In Mr E’s case it is obvious that two factors contributed to this: the factor of learning a new skill that can be used for a variety of purposes in life, and the factor of being on the edge of developments in an area of interest, which can lead to acquiring benefits from the use of cutting edge developments in science and technology.

Mr E was actually the only participant that talked about the internet. This has to be compared to the a younger generation that has grown up naturally using computers and internet and, because of the easy access to information, they do not perhaps so readily have to refer to health care professionals for information. In this case it made me think how different is my perception as well as the experience of participation. I could not help but think of myself in the future and how I would gain such information. It made me think that information giving will probably change dramatically and impact on the notion of participation in nursing care - as I am understanding it at present. Letting these concerns and questions regarding the future aside, I went on with the interview.

Mr E is the case of a single person that indicates a change in the information giving process regarding health care issues. This is the basis of the changing relationship between the patient and the health care system.

Although participants of this study did not express the opinion that participation with the use of technological advancements is going to influence future developments, it would seem legitimate and valid to interpret the above reported experience in this way.

### **Participation as a source of security**

Security was one of the benefits reported in the cases of participation in the nursing care of a family member. The interviewees stressed how beneficial the sense of security for their relatives was. This security was presented as a result of the devotion that families can offer when caring for each other.

Mrs O explained her views on security to me:

‘Ehm..., my husband...he was feeling fine, always happy. He was pleased because his partner was there and whatever he asked.....to help him change position...or anything, I was helping him because the nurse cannot sit next to him all day long...but I was there, by his side...all the time.’

‘Of course better...when somebody has a person there that is his relative...by his side...it is better. More pleasant. Is it the same thing to have a stranger by your side as having your relative by your side? This is the way these things are...’

‘Why should the nurse do these things and why shouldn’t you do things by yourself... for your husband with pleasure? You are more certain on your own...to wash him...or clean him...’

‘You have to do by yourself everything you are able to do. Whatever you are unable to do of course you will go to someone else, when you can’t do it on your own... Whatever is necessary to do it on your own it is your pleasure to do it and you are more certain when you do a thing by yourself. You can’t go to somebody else all the time....’

The interviewee pointed out that a patient feels the security that a familiar face, and family, offers and the certainty that if they can ask something from a member of their family they will be satisfied. In addition, the person who offers help feels that the family member is safe and is receiving all the help and attention needed. Providing security to family members when sick makes the family feel better. Hence a sense of beneficial reciprocity.

In other cases of participation in a family member's nursing care, security was viewed as the purpose of participation and not the outcome. Mrs U said in her interview:

'I couldn't leave him alone. He was sick and couldn't care for himself. It was up to you.... I wanted to be around and see for myself...How could I work? I would be wondering: How is he? Are they taking good care of him? What if he needs something? Is he any better? His eyes would follow me around the room when I was there...I wanted to be there...and see.'

The issue of people feeling safe interrelated with the issue of trust in the participants' stories.

### **Organisational deficiencies in the Greek NHS and their impact on participation**

In contrast to participation being about duty and solidarity with family and positive outcomes, it is also about dealing with an unsupportive NHS and dealing with difficulties. In this study I will argue that patients were under pressure to undertake a more active role in their care as there were significant deficits in the NHS such as the shortage of nursing staff. Participants gave an overwhelming number of reports about the deficiencies in the Greek NHS. The participants agreed on the fact of the inadequacy of the health care services, especially in the community. Participants reported that they suffered from lack of information, which as a result diminished their ability to participate effectively and safely in their nursing care. In addition,

they agreed on the low numbers of nurses as the main cause of this situation. This shortage reaches the extent of rareness in the health care setting.

In addition, interaction with the system was described as a tiring process and did not match the participants' expectations. Participants described how they struggled to find a doctor and make an appointment. As far as nurses were concerned, it was widely accepted that there was a shortage and they were seen as something that would be there only when absolutely necessary.

Mrs W said that the treating physician had shown her once what she was expected to do to help her husband and then she was left on her own:

'A doctor had shown me to massage him. Maybe I was not doing it right. But I was trying to do whatever was in my power.'

Mr R, clearly in distress, felt not only that he had not been adequately informed about his discharge but also that he did not have proper follow up regarding his care. He also mentioned other distressing experiences that point out the problems that are faced by health care users:

Mr R: The nursing staff, they did not give me any information at all. Imagine...before my discharge from the hospital they gave me a liquid to use in order to disinfect the rectal area and I overdid it and I got a bad burn. And nobody told me anything.

EK: Did you ask?

Mr R: After I got burnt and I could not do anything else I went to the doctor again and he told me that I got burnt from using too much disinfectant.

On other occasions, the same participant reported the following:

Mr R.: I have diabetes and high levels of cholesterol. I went to the doctor and he gave the machine to do the glucose test at home, then I was given a diet and I almost died from starvation. And even for the machine, how to measure the glucose, they did not tell me anything.

Mr R.: I have been given a diet from the diabetics unit but besides that I have not had much explained to me, what it means to be a diabetic and what to do, they just told me to do this diet and measure the glucose, nothing else...

Mr R.: Ehm...things that are simple and you can do on your own it is better to do them on your own in order to avoid queuing. Besides that there are things that it is beneficial to have a specialist check more often.

EK.: What do you mean by queuing?

Mr R.: I mean that every time that you need a specialist to ask some things, it is tiring to go, wait, and on top of that it is not certain that your problem is going to be solved. You are in trouble.

EK.: Well...as far as the nursing staff is concerned did you feel that care was insufficient or the nursing staff was insufficient in terms of numbers, causing insufficient care?

Mr R.: I would say that the nursing staff was limited. It was enough only for basic matters. Give an injection, measure your temperature and if you needed anything urgent. No, there was not plenty of nursing care.

EK.: Did you have the information you needed?

Mr R.: No, because they were always in a hurry, both the doctors and the nursing staff and you were always told few things and you were always left with questions that were not answered.

Another participant, Mr F, passionately expressed his views on what he found difficult dealing with in the NHS and evaluated the provided care:

'There are good nurses also, persons who know what their role is...There are persons who know which is their assignment. Nonetheless, these are a few. Let's say it clearly, there are...you know... thirty per cent. The other seventy per cent ehm...they consider patients mostly like...I would say...something like...a necessary evil within their work. They see the patient like fish oil. You ring the bell and the bell...Now, it could be of course that the bells don't ring...They don't show up and in general their attitude is not the one it should be towards a patient...In Greece...Besides that and they possibly ehm...as they say ehm...as they themselves say...they could be right that there aren't enough nurses in Greece, I mean often in a ...clinic when it needs thirty persons in nursing staff it might have ten and therefore ehm...they cannot respond to their duties, they get depressed and they and...they lose their interest in



their work...Now let the people who have the responsibility investigate to find out what the problem is and make it right.'

Mrs I reinforced the idea that individuals can decide and act upon the level of care they want to have not only for themselves but also for their loved ones. However, this comes with a cost in her view. Her statement shows the inadequacy of the appropriate support by the health care services:

'Look, at last my brothers hired private help. Since 1974, this is when my mother died...And there was a lady there next to my mother that was saying to me 'why should you pay for private help when you let your mother clean and fed', let's say fed and she was not eating much anyway at the end, 'you pay for nothing'. But you couldn't let her alone without anyone there as I was too tired (to do it myself). My brothers insisted also, what could I say?'

What was interesting was that some participants felt that they were forced to pay the NHS doctors themselves, because they felt that this was the only way that they could get decent health care, which added to their despair. I was deeply touched by their despair. Another group of the interviewees said that they paid doctors on their own initiative, as they wanted to show them their gratitude for their effectiveness and good work. They also mentioned that they felt that health care professionals were underpaid in comparison to other professionals and what they offered to society.

Mr J was quite open when talking about the finances of the NHS:

'When I get sick and I have to go to a hospital the first matter that comes to my mind is that there aren't enough staff to take care of me and the others [patients]. Nurses are underpaid and understaffed. I wouldn't work as a nurse. You work so hard, you don't get paid well and nobody is satisfied with your work because you don't have the time to satisfy anyone. On the other hand the number of doctors isn't so small, but they don't enjoy the best conditions either. They study so many years, they have such responsibility and get less money than a plumber nowadays...I think that they need to be paid more. Sometimes I will give them a gift because I feel that they are not paid enough. And it is a job at the end of the day...that you want to be paid for. If your pay and working conditions are bad, you have low morale and you cannot do your best. I would prefer nurses and doctor to have good morale and so I don't mind paying more.'

Mr F also focused on organisational deficiencies of the NHS that fails to meet the health care needs of old persons:

‘I will tell you something. Until now, I was not found in a difficult financial state. Because, I want to say, without being rich I was not in financial need. But because I have thought lots of times that I was born at the wrong time...because I am thinking of the others also and because I have lived, either you want the queues at IKA or you want the lists that exist nowadays at hospitals or later at IKA. Because, now IKA also in order to see a doctor...I mean to queue to IKA...ehm they have been transformed into lists...you call, you know, some phone line and you make an appointment and by this, the appointment can be set for five days, 20 days, one month later or 35 days later, that is, I think, the maximum waiting period...Because I have been going to an endocrinologist, and now in order to make an appointment I have to make it that way...So, I gave up going there any more...I am not going there again because you have to call between seven and ten past seven and if they answer and if you find this phone not beeping, you might manage to make an appointment. And to tell you the truth...I had managed it, I had an appointment with the endocrinologist but the day I went I made the appointment for 35 days later. The day I went they were on strike and my appointment was cancelled. And I said, what the hell...it is over. It is not worth it to be involved with all this...Well and the queues have been transformed into lists. Ehm, personally I have the impression that the benefits...the medical benefits for the Greek people instead of improving, unfortunately they are getting worse. Unfortunately...’

### **Dealing with disappointment in the care provided by the NHS**

Another widespread feeling among participants in my study was their disappointment in the NHS and health care professionals about the quality of care provided. Doctors and nurses had disappointed the patients and contributed to making the old persons feeling powerless when dealing with the health care services. This disappointment led them to start rejecting the services and being critical or even dismissive of health care professionals. The non-verbal communication gave more evidence on this issue than any statement. I could see in their expressions and body posture when talking about the provided health care that they were deeply

disappointed. Their feelings were crushing and they affected me deeply. Sometimes a picture is more powerful than a thousand words.

Disappointment with the NHS appeared an equally powerful motive for old persons to participate. Some participants explicitly told me during the verification interviews that since they were not being given the health care they deserved and ought to be given by the national health care system, they should assume control for the situation and do the best they could by themselves. One of the participants said that the only way to ensure things were done correctly was to do them yourself.

Mr F clearly stated his disappointment with the NHS:

EK: How does that make you feel?

Mr F: Disappointed...as I have said before.

Verification interviews, enriched the data regarding issues concerning the NHS where feelings of dissatisfaction were frequently mentioned. Some participants did point out that there had been progress in the health care sector but that more should be done. Some of the participants wanted to be more positive about the NHS and what it offers to society reflecting those that do not express feelings of disappointment about the NHS. These, it can be argued, are those with a very positive attitude expressed by identifying the improvements in the NHS and the opinion that you cannot expect perfection in real life.

However, even the respondents that were more positive about the NHS expressed doubt about the NHS and the health care professionals. Specifically they expressed the concern that, if they needed an NHS service, they were not certain that they would be provided with the appropriate care.

In verification interviews the participants enriched the data not only by their experiences to justify their opinions but also with stories that had been reported by the media, especially television. Obviously the media had a strong influence in shaping their opinions. This was an interesting point as they themselves were not

willing to give their story to the media as they considered it embarrassing. From the beginning of the research process, the participants were eager to make sure that what they said would be kept confidential and to be reassured that I had nothing to do with journalism.

## **Participation and frustration with the NHS**

This study suggests that interviewees felt frustration as they reported that they did not have NHS support that would enable them to participate and make choices. Participants expressed their frustration at not receiving adequate support by the system to perform tasks that had been delegated to them by health care professionals. These accounts brought back memories from my late grand-parents when they were complaining about similar circumstances. Some things might have been familiar in these interviews but I needed to keep a fresh mind, retain *epoché*, as if I knew nothing, and probe more deeply to obtain a full account of their experiences.

Mr R recounted a series of experiences that not only presented his frustration but justified it:

Mr R: I have diabetes and high levels of cholesterol. I went to the doctor and he gave the machine to do the glucose test at home, then I was given a diet and I almost died from starvation. And even for the machine, how to measure the glucose, they did not tell me anything.

EK: Is there any case that you co-operated with the nursing staff?

Mr R: I was co-operating, they did not care...

EK: This experience...how did it make you feel about the nursing staff?

Mr R: I felt really bad. I really wanted to sue them but I couldn't because I was a sick man and as you can understand I suffered for about a month until it was over.

At a later point in his interview he said:

“When you have a health problem it is the worst moment. Consequently, as you understand, this is when a man needs support and care. When somebody is fine, he does not need anything. This is why I felt bad every time I had a problem and nobody was doing anything with interest and my stress was increasing and fear of what is going to happen and all this....”

This study suggests that patients were not given information or any opportunity to make informed choices. Interviewee accounts demonstrated frustration as they reported a lack of support to participate and make choices regarding their health care.

Another participant, Mrs Y in my study expressed her frustration in a more detailed way and described attitudes and perceptions that she observed:

“I am just an old woman....I don’t want to bother (anyone)....if I am not well (in my health), what am I going to do then....there is no disease “old age” to die from. They don’t tell you and then I don’t want to insist....you feel like you are a nuisance....if I am not told how do I know....something to do right for myself.”

Although in my study this was not explicitly reported, there were instances in the verification interviews that revealed that the old persons themselves were not paid much attention and their relatives were informed in more detail than they had which made them feel deeply frustrated.

Although there was a widespread feeling of frustration among participants, not all of them expressed the view that their old age was the factor that determined the attitudes of health care professionals towards them. Several of them thought that this was a reality in health care for all patients, regardless of their age.

### **Participation and distrust towards the National Health Care System and the health care professionals**

Distrust can be viewed in relation to the organizational deficiencies of the NHS. Not all of the participants talked about the feeling of distrust towards the NHS. Old



persons tend to distrust not only the NHS as a system but also health care professionals as far as their professional ability and expertise are concerned. Moreover in some cases they were critical even about their intentions.

Distrust is presented as an incentive to participate in health care. The lack of trust between the service provider and the service recipient motivates people to be more actively involved in their care and seek assurance by verifying information given by health care professionals. I felt uneasy being told that health care professionals are not trusted. I had never thought that I could be seen as someone that would make a mistake; it affected my self-confidence as a nurse. I had to put my feelings aside and concentrate on the interview, although I felt uneasy.

One of the participants, Mr F, expressed his views on the issue as follows:

‘I am, I am suspicious but I am not suspicious as far as the doctor’s intentions are concerned but it’s the medical mistakes which I am scared of. I am often scared of these medical mistakes. I ask a lot and I want to be close to the doctors and ask and a lot of the time I ask as if I am dumb. I ask for example to verify what he told me in case I did not understand it correctly, in case he did not express himself correctly, in case...in case...in case and I might also ask a second and third doctor to ehm...make sure. Because always...I do not have this self confidence I should have...that I would like to have.’

## **Participation as a burden**

As well as the benefits of participation, which I have mentioned already, can be an experience that can have negative consequences on people’s lives. This applies especially in the case of a person who has adopted the role of a carer for a loved one.

This study has shown that participation in the nursing care of another person can become a time-consuming commitment that can be viewed as a burden. There were cases where spouses who have assumed the role of the carer for a long-term patient in the community, view participation in nursing care as a negative experience,

specifically as a burden. Mrs W expressed her own experience of caring for her husband, in our discussion:

‘I didn’t go for a walk outside for twelve years.. In the meanwhile he was feeling insecure and wherever I went if he didn’t have me in front of his eyes he was calling for me...’Mrs W!’ ‘I’m coming’. Ehm, I was cooking, washing, you know...I was not always at home. He was calling for me...’

Mrs W gave more details of the demanding nature of her task:

‘I did not even get out of the door. I was waiting at the door for a neighbour to pass by and tell her ‘bring me a bit of bread because I can’t go’. And for the medication I went...sometimes I left him alone, sometimes my daughter told me ‘don’t leave him alone mum, I’ll go’ or my daughter-in-law. Whoever was available.’

Participation in nursing care in some cases might develop into a long term process with serious consequences for the care givers’ whole lives. As expressed above, Mrs W’s role became hard to bear as it impinged on her everyday activities and stopped her doing things she liked or even necessary things such as going to buy groceries.

Participation can also take the form of financial participation in the cost of care and this can become a distressing burden. This is an experience that should be viewed in relation to the structure and characteristics of the national health care systems. Not all national health care systems have provisions for nursing care in the community; in others, the provisions for care differ wildly from community to community, depending on the available resources and how well these are managed.

Mr S expressed his distress about the financial burden that participation can sometimes prove to be. Furthermore, he pointed out that the system was not adequate to meet their health needs. In his case, no services had taken any action to meet needs of himself and his wife in the hospital or the community setting, which left him with no other option than to pay for nursing care:

‘Let me tell you now, I was in hospital and while I was in hospital my

wife got very sick also and we couldn't do anything at all for ourselves and we were spending one thousand six hundred euros a month, per month and of course in addition what I spent on the doctors. I went crazy. I had a small pension and it is gone...I got sick after so many years...and I have my wife that has to stay in bed. I didn't see anyone come and knock at my door. I worked for forty years...Many sacrifices for the family. I have climbed up to ninety metres high without a safety net...They say 'you have to take all the medication', pay the bills, pay for care assistants. When I was in hospital I had three. I was paying one hundred and thirty two euros per day.'

In the same vein Mr F said:

'I have the impression that the benefits...the medical benefits for the Greek people instead of improving, unfortunately they are getting worse. Unfortunately...'

There are old persons that suffer under the heavy financial burden of professional nursing care. The cost was something that participants were concerned with and it was emphasized in the verification interviews. Participants reported that they needed to spend money on hiring private nurses and carers to make sure that they and their loved ones had adequate nursing care in both the hospital and community setting. In this study they reported inadequacy of the services and the provision of nursing care in both the hospital and community to the point that they felt obliged to take action and suffer a financial burden in order to offer the necessary care to their families. When they were asked about participation in nursing care they immediately expressed their dismay about the financial burden they suffered or still suffer. For them participation in nursing care took the form of financial participation. Greek patients have to deal with the financial burden that a mismanaged national health system bestows on them.

The verification interviews, emphasised their anxiety about the financial burden that accompanies illness. They also stressed the fact that at their age they were concerned with money as they did not have the ability to earn extra money by working, for example, in a second job, as they would do if they were younger. Instead they had to rely completely on their pension and, if they are lucky, on the money they had put aside when they were younger. In general, the participants agreed that financial

issues as well as ideas of reward and control over their lives made them willing to participate in nursing care. They pointed out that, depending on the situation, the importance of each factor varied. What was clear was that the issue of money for health care was a significant preoccupation for them.

They were concerned about the implications of their financial status as they felt they could not trust the health care services to get the help they would need. In addition, they felt very uncomfortable with the idea of being a burden for their children. They felt that they would have to rely on their children if they were in need, which disheartened them as this was a new reality they were reluctant to deal with.

Although they all agreed that participation in nursing care was a positive attitude, as reported from the findings, they did not expand on this view. They were preoccupied mostly with the financial burden either as a reason for participation or as a consequence of illness and associated this with high levels of anxiety and emotional fatigue. One of the participants stated that an illness could make them feel exhausted but issues concerning money made them feel desperate; especially if their children were not able to help them.

### **Participation as a cause of anxiety**

As I have already argued, participation in nursing care does not have only positive outcomes. The participants said that they were very anxious when they first participated and when they started undertaking challenging tasks or initiatives.

Mrs W said in her interview:

EK: On your own....Did you feel stress? I mean out of the blue you found yourself in the situation that you had to take care....

Mrs W: [interrupts] In a way yes, because I did not know everything. I was not a specialist. I was not a doctor. But I was asking the doctor....I was asking the nurses...."What should I do for him?" I was

going from hospital to hospital. I was asking what to do. One would tell me 'do that'. I was trying, doing everything I could. I made an effort. I tried whatever I could to do it right; his pills at the right time, massage his feet, his medication on time, give him his water, everything. Everything...'

Mr R felt that his anxiety was caused by the inadequacy of the health professionals that forced him to take on a role that he was not prepared for:

'When you have a health problem it is the worst moment. Consequently, as you understand, this is when a person needs support and care. When somebody is healthy, he does not need anything. This is why I felt bad every time I had a problem and nobody was doing anything with interest and my stress was increasing and fear of what is going to happen and all that...'

Mrs O expressed her concern about the outcomes of her acts:

'Eh, for all these? Oh no...It is my satisfaction, just do it...It is not an issue. Of course you get stressed if you do it right, if you don't do it right and what will be the result and all that...this is how it goes. It is also satisfying. It is nothing unpleasant.'

The above quotations demonstrate that participation in health care does not have only positive outcomes.

In my study the participants showed high levels of awareness of the above risks and this resulted in making them feel anxious. In their cases anxiety was compounded by the organizational deficiencies of the NHS.

### **Participation causing fatigue to those involved**

As well as being highly satisfying, participation in nursing care can be demanding, therefore tiring. This is particularly the case for frail old persons and those with general health problems. Fatigue can be both emotional and physical. This is an element of participation that has not been thoroughly investigated in the literature.



The main consequence could be neglecting to perform tasks that are essential for the maintenance of health and prevention of disease.

Mr H said regarding participation in his nursing care:

‘Well...even if I want to...my body is now willing but not capable of doing...You know the saying...I wake up in the morning and it is difficult to get started. All these years. I feel too tired even to measure my blood pressure. I don’t even want to look at the blood pressure machine.’

Some of the interviewees stated that due to their health problems they had seen some deterioration in their ability to help others as well as themselves. Mrs K used to visit one of her friends and help her with errands. She started to feel however that she would not be able to continue:

‘My feet cannot hold me any more as they could in the past. I cannot do the things I used to. I have even started thinking of not going this week to visit X. I feel bad but what can you do...She needs company but I am not as strong as I used to be. Lately, just taking care of myself makes me tired...let alone going around as I used to.’

Nurses are under pressure to involve persons in nursing care but they have to bear in mind that limitation in abilities due to ill-health can lead to persons receiving inadequate nursing care. To this we can add the data of this study which implies that fatigue can be another reason for self-neglect.

This study suggests that the Greek national health care system has considerable organizational deficiencies that oblige patients to be actively involved in their health care in order to be able to meet their needs.

#### **4.4 Summary**

In this chapter the meaning of participation in nursing care was examined. It was clear that participation was experienced with an extraordinary diversity. Participation as a phenomenon is seen as a whole, in view of the persons involved and the setting that it is experienced within. Participants viewed participation as a continuum that covered the settings of both hospital and community and extended to members of their families as well as their friends, neighbours and members of their communities, forming a circle of support.

It was seen clearly as having both positive and negative aspects. Participants reported that through participation they were felt a control over their lives and gained power over interpersonal relationships with health care professionals. In addition, they had feelings of reward, satisfaction, fulfilment and achievement and a means of personal development. People also expressed gratitude for help that had been offered and in turn they felt gratitude from those who had been helped. On the other hand participation was reported to be a burden, both emotional and financial; it could also be a source of anxiety and fatigue. It has also been presented as a consequence of disappointment with society and the NHS, and hence a result of the organizational deficiency of the NHS. By this token, participation is associated with frustration and distrust towards the NHS.

Dealing with their ill health or maintaining their health has been the challenge that old persons have to meet at this stage of their lives. They mentioned that their system of beliefs and experiences of historical events had influenced their viewpoint. Even when they did not mention this in detail they did give evidence that they connected their participation in nursing care with other major life events that had formed their character or even circumstances of life. It was evident that the beliefs that participants had adopted in their lives as well as the historical events they had lived through did not constitute participation but did colour its demonstration.

Participation is a diverse phenomenon that seems to be still evolving and it is manifested in different ways according to the environment in which it is demonstrated. The phenomenon as experienced by the participants of the present

study might not be the same for future generations not least by virtue of technological advancements such as the use of the internet.

## **CHAPTER 5**

# **DISCUSSING THE STUDY AND IMPLICATIONS FOR NURSING PRACTICE AND RESEARCH**

### **5.1 Reviewing the study**

By researching their lived experience, this study has explored the meaning of participation in nursing care for old persons living in the community. The aim of the study was to gain an understanding of the meaning of participation in nursing care for old persons and thus improve nursing practice, influence policy planning in the health care sector promote person-centred philosophy and initiate more research in this field.

An extensive literature review regarding participation was presented and the gap in the already existing knowledge was identified. It is obvious in the literature review that participation is a subject that has been studied from a number of perspectives such as those of nurses, health care professionals and, of course, old persons. Nonetheless, participation and its meaning for those who participate, have not yet been clearly defined. The literature review demonstrated that the meaning of participation for old persons living in the community is an area that still needs to be researched.

Research that has been done which investigated the phenomenon from the point of view of both old people and health professionals found considerable differences.

Although there has been research conducted regarding participation, no such research concerning old persons and participation in nursing care has been conducted in Greece.

The theoretical framework and the research process of this research study were explored. I presented my research design and implementation in detail so that the reader can be fully informed not only about the findings but also about the way in which this research project was implemented. Phenomenology was identified as the appropriate approach to investigate the research question. Finally, the findings have been presented through the participants' own words.

This study is significant because it is the first study that explores participation in nursing care in Greece. For participation to be implemented in nursing care, nurses have to understand old persons' views and experiences and what these mean to them. This study contributes to that by researching the meaning of participation in nursing care for old persons living in the community. It supports studies that have investigated the phenomenon earlier and it adds to them by the new messages that are revealed.

Moreover, this age group needed to be studied as there are challenges such as ageism that differentiates this age group and we needed to focus on the community as it is an area that is still developing for nursing and it has significant differences to that of a hospital. Let us not forget, as discussed already (see p. 27-30) that the growth of the old population, the change in family structure and technological advancement could all have a detrimental effect on future societies. These reasons all underline the importance of investigating old persons' views and experiences on participation for the planning of future services and most importantly, the offer of more effective services in the present.

In addition, focusing on the meaning of participation contributes to the better understanding of the phenomenon in general for health care professionals. In the Husserlian phenomenological approach, phenomena are studied as they appear



through consciousness, and experience is considered as the ultimate ground and meaning of knowledge (Cohen, 1987; Koch, 1995, Walters, 1995). According to Hallett (1995), the value of phenomenology lies in the fact that it focuses on participants' perceptions and gives the researcher the opportunity to gain an in-depth account of the researched phenomena. Furthermore, as Jasper (1994) commented the focus of phenomenology, which is clients' experiences, means this approach can be used to plan future care because it enables clients' needs to be identified. Therefore, the results of phenomenological research can contribute to the provision and justification of high quality care.

## **5.2 Methodological challenges: implications for research**

Phenomenology was not an easy choice to make as it poses challenges to the researchers that use it. First of all I had to choose among a variety of approaches that although they are all characterised as phenomenological they have considerable differences (see p. 93-98). For example the Husserlian approach says that bracketing is possible while on the other hand Heidegger, who developed philosophical hermeneutics, argued that bracketing is not possible and the researcher's 'pre-understandings' are brought to the text. Such antitheses within the same approach, makes it hard for novice researchers, such as myself, to choose the appropriate approach for a study. I had to think a lot about my research question and my aims as these would determine my approach.

Let us not forget that there is a heated discussion regarding the application of phenomenology (as discussed in p. 106-112). Crotty (1996), Paley (1997, 2005), Barkway (2001) criticised nurses for their use of phenomenology. Crotty (1996) argued that nurses do not perform phenomenology but yet another type of research developed by North American researchers. On the other hand Lawler (1998), Giorgi (2000a, 2000b), Dermot (2000) responded to their criticisms, defended the present use of phenomenology and attributed such criticisms to misinterpretations of the original texts.

Furthermore, more issues are present in the literature such as the use of the secondary and tertiary sources (Cohen, 1987) and misunderstandings in the use of terms specific for phenomenology (Corben, 1999). Porter (2008) suggests that all these issues regarding the use of phenomenology cost nurses a lot of time and effort that are not necessarily justified by the results of the method. When this discussion exists in the literature it is not possible to perform a study and ignore it. I read all about it and it made me feel that I needed to demonstrate appropriate use of terminology, avoid the use of secondary and tertiary sources and defend my use of Husserlian phenomenology.

In addition, I felt that I should be able to demonstrate that I am aware of the theoretical elements of the approach and that I am able to use it correctly. Although in a PhD theses, terminology should be avoided I suggest that in this case that there is so much discussion regarding the phenomenological terminology, terms should be used as an exception (and be explained by going back to the source) so that the readers can judge for themselves whether I have understood and used phenomenology rigorously (Rolfe, 2006). Moreover, I realised that I needed to read papers carefully and always refer to the source.

As it appears, phenomenology is not an easy option to make when someone is choosing a research approach. Personally I have to admit that I was persuaded as to the value and the potential of the method, especially that of bracketing in offering the unbiased truth of phenomena as experienced and viewed by the participants. I strongly believe that nurses need to offer more such research to improve their practice. In addition, I suggest that we should not overestimate the value of the inclusion of the personal reflections of the researcher. The truth lies in the data and not in such insertions researchers disclose as much as they want as it is not possible to verify these. I find bracketing a better way of dealing with such issues.

Nonetheless, performing epoché was difficult, but feasible. I believe that I have managed it within human capabilities. Perfection does not exist. Arguing for the

perfection could make other approaches not feasible. Theoretically, as explained (see p. 115) people can perform epoché because they are aware of the different roles they have. Looking back I can say a crucial point was when I realised that I cannot stop myself from feeling and I cannot erase what I know, but I can become aware of these in the best detail I can and keep them away from the interview process and analysis because I am aware.

I could feel for example, the participants' frustration that was caused by the deficiencies of the NHS but as a researcher performing Husserlian phenomenology I should not influence them by my own views and feelings. This has been an on-going effort throughout the study. I found out that it is only natural to slip into exchanging opinions or taking position during an interview or sometimes reacting without even realising it. I had to stop myself several times. I found it challenging as I visited them at home and we had already met once or twice to give information and arrange the meeting. They wanted to know me, asking questions and some seemed so familiar as they reminded me of my grand parents. It is apparent that in this context I had to be alert and maintain the interview uncontaminated by my preconceptions and feelings.

Another point that I found challenging was rigour. Rigour has to be relevant to the research paradigm that the researcher follows (Denzin and Lincoln, 1998). It is clear in the literature that qualitative research has moved on from the use of quantitative criteria to using new ones that have been developed for qualitative studies. At the same time, it is apparent that rigour is something that cannot be prescribed in qualitative research for all its approaches hence there is not a common set of criteria in the literature (see p. 99-103).

In this study, using Husserlian phenomenology means performing epoché throughout the data collection and analysis, consequently, keep the process uncontaminated by my views and perception. Using Colaizzi's method of data analysis means that my analysis was validated by the participants. Nevertheless according to qualitative standards I had to describe clearly how I obtained my data and how I analysed them. Husserlian phenomenology is about putting my views on the side and not in the

middle. Thus, I needed to be honest and transparent throughout the study but at the same time avoid focusing on myself at the expense of the participants. At the end though it is up to the reader to decide whether this is a quality study as Rolfe (2006) pointed out.

The reflective diary that I kept throughout the study was another helpful and significant part of the research as it became a useful multipurpose tool. It was used as a diary to keep track of appointments as well as a reflexive journal in order to maintain rigour and record my own thoughts, feelings and discussions during the research process as a way of continuing epoché. I have entered few examples into the text, and I also used it as a resource in the writing up. As this is a theses and not a diary, I have used the data from the diary throughout the study.

Here, I have to acknowledge that I understand that at different times the interviewees would probably tell me different stories, I could have produced different themes and if the researcher was somebody else there would be a different interview produced. Moreover, having in mind that people have the tendency to say what they are willing to say it required a leap of faith to listen to their stories.

This study has tackled another important issue, that of translating research. I had not only to report the findings but also to communicate both the theoretical framework and the research process to the readers in a different language to the one in which the study was performed. I realised how important it is for nurses to understand (especially nowadays that research is communicated globally) that translation is closely related to issues of rigour and be aware of the problems that exist when researchers need to translate their studies in order to communicate their research.

Looking back, now that I finished the study I can say that this has been one of the most difficult parts of this study. Having to write about the findings in English while I gathered the data in Greek, it was not expected to be as difficult as it proved to be. As I have already explained it was more than just being lost for words, it is finding the best word in English to translate what I found in Greek. This process has been

extremely difficult as the proof reader/translator will help and tell you if something does not make sense but I knew my data and I did the analysis, and I had to choose the right word from a variety of synonyms in some occasions. Sometimes the difference in the meaning of synonyms is so subtle that for me that I was not a native speaker was not so obvious at first. Translating idioms was also hard.

Practical issues regarding translation from Greek to English were explored during the pilot study and an extensive literature review was performed in order to investigate the related issues. Koskinen (2004), in her paper about trends in translation, stated that translation is done across cultures and not languages as languages are developed within a cultural environment and words represent concepts that are developed and understood within a context that might not be commonly understood by all cultures (see p 104-106).

One thing I would do differently, would be interviewing nurses as well so that we can have a fuller picture of the phenomenon. Giving voice to nurses in a Husserlian phenomenological study would give the other side of the story and we would be able to have a fuller picture regarding participation, as well as the action that needs to be taken in order to improve nursing practice.

Another thing that I would do differently, would be interviewing less participants but I would aim to perform more follow-up interviews with each of the participants. I found out that after the first interview the ice breaks and it is easier to interview in more depth. This would give me the opportunity to explore the issue of fatalism (see p 199) I did not include in my analysis due to the strong reaction against it the study participants demonstrated. This strong reaction against fatalism could mean that it was an important element of the phenomenon of participation and the second interviews could be used to reveal it. To be able to explore this I would have to engage in a dialogue and employ a hermeneutic approach that would move me away from the Husserlian phenomenological approach that I used in this study. A hermeneutic approach would definitely add a significant aspect to the issue under



investigation. Thus, my Husserlian phenomenological approach can be considered a first step but more research is needed.

Moreover, as it is said earlier, in this chapter, there is a heated discussion (eg p 95-100, 107-108) concerning the application of phenomenology in nursing research, which I have taken into consideration, and this study is nonetheless a product of the current debates in research. I have made my choices and conveyed them to the reader but as explained earlier (p 99-105) it is up to them to decide whether this study has addressed the raised issues.

### **5.3 Moving the debate forward: implications for practice**

#### **5.3.1 The changing face of participation**

Although this study has produced interesting results it has not given the essence of participation that can be understood and prescribed universally. Instead a fluid, multi faced, changing phenomenon, influenced by a variety of socio-cultural factors, including time and setting was revealed. But this could be exactly the nature of participation, fluidity. Moreover, this could explain why there is so much debate in the literature regarding the meaning of the phenomenon. Participation could be a phenomenon that needs to be fluid as the means of dealing with ill health in modern societies that chronic incurable diseases and old age are increasing while the traditional model of health care that wanted health care professionals providing and the sick people undertaking their passive sick role cannot deal with the increasing demands and the changes in societies. Thus, a change is needed and new mechanisms to start being in place, such as participation in nursing care.

It has already been explained that since the 1970s, the Declaration of Alma-Ata drawn up by the World Health Organisation has had a significant impact on national health care systems (Zakus and Lysack, 1998). The Declaration of Alma-Ata raised awareness of the problem of the inadequacy of hospital-centred care to achieve

health in the modern world. Community participation was presented as a step forward that would help modern states to solve significant health care problems (Zakus and Lysack, 1998).

Since the declaration of Alma-Ata of the World Health Organisation in 1978, significant changes in national health systems all over the world have been implemented. In the past patients were viewed as 'passive recipients of nursing care' (Biley, 1992; p 414) and when a person became sick it was assumed that this person would be entirely dependent upon health care professionals. Parsons (1957) argued that a sick person would not work or undertake activities and would rely on health care professionals in order to get well and return to their daily routine. This theory has influenced medical thinking as a theory that has both been strongly supported but also triggered significant opposition (Cahill, 1998).

Since then a significant change has occurred, not only within health care but also in society in general. Society has gradually accepted a new norm regarding autonomy and individual responsibility (Ashworth et al, 1992). There is literature which claims that many of the major causes of morbidity and mortality are lifestyle related and therefore preventable (Latter et al, 1992). Demographic trends also result in a focus on maintaining the ability to be self-reliant and to maintain health over the longer lifespan that most people can now expect. Therefore, according to Latter et al (1992), the proportionate increase in chronic, incurable conditions as well as the growth of the ageing population makes it necessary for individuals and their families to be encouraged to participate in their care and manage their own illnesses, which is reflected in policy directives.

Simpson (1997) on the other hand mentioned that the traditional health and welfare state is still based mainly on one group of service providers making decisions for another group of service users and that has as a result services that people experience as paternalistic and disempowering. There is still a clear criticism that health care providers tend to give the passive sick role to their service users. There are contradicting statements in the literature. This was evident in the interviews as well.

There has been though reported in the present study that the hospital setting and the health care professionals in hospitals are still paternalistic and disempowering, as described by Simpson (1997). On the other hand, it was reported in the present study that the community setting reinforces old people's ability to become empowered and participate in their nursing care.

Kirk and Glendinning (1998) claimed that formal and informal nursing care is expected to change dramatically due to the shift of hospital care to community (home) focused care. Although there is an increasing incidence of informal carers taking over areas of formal care-giving, appropriate support networks are not in place. Therefore, questions regarding the benefits and the drawbacks of this situation arise. The authors mention that there are concerns about whether this practice is ethical at all times and whether there is adequate support provided to users. Whilst their concerns are valid, there is a need for more research to address the issue in more depth.

### **5.3.2 So, what is participation**

This study enhances the definition of participation as presented by Brearley (1990), Brownlea (1987) and Peplau (1988). This study points out that these definitions complement each other. The new message from this study is fluidity. The nature of participation is fluid and adapts in any case in order to cover the person's needs. Participation is viewed in a continuum and it does not stop because a situation is changing, for example being admitted to a hospital.

Participants of this study did not limit their descriptions to the community or a specific aspect of nursing care. They referred to both community and hospital settings, involving different persons as participants, performing a variety of tasks, each to a different extent, as well as taking initiatives regarding their nursing care and treatment. They even evaluated the care that was provided to them by the

national health care system. Another aspect of participation that I identified in the interviews is that of decision-making.

The diversity that characterises participation is not new in the literature. It is apparent that even though the international communities talk about community participation, there is not yet a well-defined conceptualization for the term. Zakus and Lysack (1998) pointed out that community participation in health care can be demonstrated in a variety of ways and can range from persons who become passively involved in specific known activities to those who are in control of organizations.

When participants explained what participation meant for them, they referred to the delegation and performance of tasks, decision-making, or even the creation of choices as actions of participation. If these are compared with results of the literature review (see p 33-38), common characteristics as well as differences can be found. First of all, in this study participants did not make a distinction or place the aforementioned activities in a hierarchical relationship, as in Cahill's concept analysis (1996).

Although a concept analysis (Cahill, 1996) is a significant contribution to nursing knowledge, it is written by and for nurses. In the study patients did not make any reference or distinction regarding the associated concepts of collaboration, involvement and partnership that the study presented as having a hierarchical relationship. This is again a useful categorization for nurses who are investigating the phenomenon but it is not how things are viewed by the participants. The conceptual analysis might be useful but it is not how participants viewed participation.

The same researcher conducted a literature review regarding participation in nursing care. It found that the majority of studies belonged to the positivist paradigm and little qualitative research had been done. Although in recent years qualitative research has been done, there is still the need to explore patients' views on the issue to illuminate its nature so that nurses can be certain about how participation can be implemented in their practice.

### 5.3.3 Circle of support

This study revealed that there is an inadequacy in the provision of health care in the hospital setting that is compensated for by the participation of the community, often in the form of a circle of support. In this case, participation is a necessity so that the health needs of the community can be covered. This is far from the ideal community participation that was expected to develop by the World Health Organisation (see p. 56-58).

It is also clear in this study that old persons in the community form a circle of support with friends, neighbours and family and depend heavily upon it to meet their needs. This is based on the serious NHS deficiencies that fail to cover their needs, the positive outcomes of participation that act as positive reinforcement and their system of beliefs (political, religious, moral) that are culturally rooted in the community (see p. 170-218). Thus, historical events and their impact need also to be taken into consideration when creating services for old people as they constitute influential background factors.

The association of participation in nursing care and social capital is an issue that was discussed in the literature review. There are researchers such as Bubolz (2001) that pointed out that the family is not only the starting point for social capital but also the beneficiary and maker of the social capital. It is argued (Cowley and Hean, 2002) that it is beneficial to people to live in communities in which neighbours know and trust each other and where a cycle of support is existent (people help others knowing that they are also going to receive help in return at some other point). Furthermore, trust is argued to be the basis of behaving in a moral way which leads to the creation of social capital (Kumlin and Rothstein, 2005; Bubolz, 2001).

Hyypä and Mäki (2003) performed a quantitative study in Finland to examine whether there is a relationship between social participation and health in the



Swedish-speaking minority living there. They concluded that the Swedish-speaking community, which was characterized by a strong community ethos (i.e. was rich in social capital), was associated with better self-rated health. Moreover, it was demonstrated that socially active persons are more often active participants in health care. Their results were congruent with earlier results from research performed in other communities (Veenstra, 2000). It is argued (Cowley and Hean, 2002) that it is beneficial to people to live in communities in which neighbours know each other and they trust each other and a cycle of support is existent (people help others knowing that they are also going to receive help in return at some other point).

Community services can vary according to the family and social support that a person receives in the community. Policy makers have begun to realize that a shift from acute health care provision to community care is necessary. This is facilitated by the advances in both medical and nursing practice. It has however become a necessity due to the increasing demand for quality health care services while resources remain limited (Tinsley, 1998).

Bearing in mind the growth of the old population to its highest ever levels, health care services need to take into consideration the value of the existing social capital and use existing circles of support in order to meet health care needs in the community in a safe and efficient way. This study shows that there is a need for flexible nursing services that will provide information and training in the community to old persons that are in need of nursing care or are willing and eager to provide it to someone close.

The increasing demand for nursing care should not allow participation to be developed without professional support. Nurses can have a consulting role in such cases to make sure that nursing care is provided in a safe way to as many people as possible. It is apparent in this study that old persons do value having control over their lives and they consider participation in their nursing care as crucial in accomplishing their aim of being empowered. Nurses thus need to know not only their patients but also the environment that surrounds them. They need to know the

amount and quality of support that patients are likely to receive and if needed take action to improve this, in order to maintain a minimum standard of care. The mechanism that will enable this to be achieved remains to be decided; it could be on an individual level or involve group seminars on common issues. To put it succinctly, participation should be a symbiotic change among nurses and health care users. Nurses need to adopt a phenomenological stance in their nursing practise.

### **5.3.4 Technology and participation**

Participants in this study reinforced the voices of those that place increasing emphasis on the significance of the use of the internet by health care consumers. The significance is reflected in the fact that in a group that has a high illiteracy rate, there was still someone to use the internet to gain quick access to health information and the appreciation of its capabilities. This indicated future developments.

Levin-Zamir and Peterburg (2001) mentioned the term 'health literacy' which in two words summarizes the change in society that is increasingly dependent on technology. Moreover, Malone et al (2004) argued that rapid growth of the internet has also had a detrimental effect on patient participation due to the wealth of information that is easily accessible regarding health issues. This study has found that patients are eager to know more about their health and care and they are willing to use modern technology to achieve that.

Hence, nurses need to consider adopting technological advancements such as the use of the internet, which will continue to grow in significance for those interested in promoting participation. Scientific progress affects all aspects of life and can provide solutions to inabilities that in the past caused physical impairment and needed constant nursing care. It is expected that in the years to come more old persons will be able to stay in their homes and enjoy independent lives without being under pressure to move into a nursing home for continuing nursing care.

### **5.3.5 Viewing participation in context**

Problems that exist in health care systems can have political or even historical and cultural origins, or they can be intensified by these factors (Morgan, 2001; Zakus and Lysack, 1998). Another issue concerning participation that anthropologists have pointed out is the significance of factors like gender, age, ethnicity, religion and economic status of the community members that practise participation. It is argued that all these have a significant effect on the implementation and manifestation of patient participation in the community (Morgan, 2001). There are differences in the way in which the phenomenon demonstrates itself under different circumstances or even in another age or cultural group. Today however, such changes are minimal, as a result of globalization. Like other countries, Greece has similarities and differences in the development of the phenomenon of participation in the community. In this study participants expressed their social, religious or political beliefs in relation to participation. Lived experiences are coloured by all the above and they need to be taken into consideration.

Nurses need to take into consideration the ideological and cultural background of those that are involved in nursing care, in order to avoid insulting them, provide appropriate care, to behave in an appropriate way. It has been pointed out in this study that religious beliefs or societal pressure can be powerful motives obliging people to care for others. Filial duties or marital obligation can also be strong motives but they can also cause suffering to those involved.

Nurses cannot force people to act against their beliefs but they need to discuss any such issues with those involved and lessen the burden where necessary. It was seen in this study that in Greece, children who place their parents in a care home are viewed in a negative way by the rest of the community and it is considered to show a lack of love for one's parents. In such cases nurses and the public need to discuss and find solutions that are acceptable by all sides, having as a priority the well-being of

those involved. Moreover, nurses need to take the above issues into consideration when designing nursing services for old persons.

There are studies that attempted to determine whether old persons prefer to stay in the community and participate in their care or the care of a relative. The results were in favour of staying at home. Nolan and Dellasega (1999) recognized the increasing need for nursing homes, while the significance of continuing family involvement was stressed. The study also revealed that participants saw the decision to place a loved one in a nursing home as a very difficult one, with long term consequences for all involved.

The participants in this study also mentioned that caring for the old at home was preferable. Nursing homes were not seen as very appealing and the provision of care to the old at home was presented as the only option participants would consider, unless there were exceptional circumstances. Participants were quite concerned by what would happen when they would not be able to take care of themselves.

Some research has criticized the Greek national health care system for its organization, structure and efficiency. Ballas and Tsoukas (2004) studied and criticized the Greek NHS. They wrote:

‘The traditions of patronage and favor peddling, firmly entrenched during Ottoman rule, have been carried forward in the form of clientilistic practices, based on the measure of kinship and locality...we see this in the largely clientilistic relationship between doctors and patients, and in the governance structure and staffing of healthcare units. The Greek system is highly politicized and it is neither effective or efficient.’ (Ballas and Tsoukas, 2004, p 682).

Ballas and Tsoukas (2004) also suggested that doctors’ unions are powerful and influential organizations that aim to serve the interests of their members and not the general good. They tend to oppose any attempts from the Government to reform the system. They maintain the power of doctors in the NHS so that they can keep taking their ‘fakelaki’, the small envelope full of cash (Kyriopoulos and Tsalikis, 1993) and

maintain their questionable relationships with pharmaceutical companies. Furthermore, it is mainly doctors who are given the management of hospitals.

Edwards (2000) argued that patients should have an active role in their care and treatment in the reality of modern health care for a variety of reasons including a political aspect. Such views are expressed by professionals but, arguably, these do not represent the feelings that the public shares. None of the participants approached participation as described by Edwards. They did relate political beliefs to the phenomenon but they did not make any connection between cost effectiveness and participation or ethics. In addition, it is evident that political beliefs of participants in this study influenced the demonstration of the phenomenon of participation. The variety of belief systems that each person holds and which may influence the demonstration of participation could explain the diversity of the presentation of participation.

In addition, there is the strong feeling that it is a sin not to take care of your body as this is the temple of the soul. Therefore, participants think it is essential to undertake all the necessary actions to maintain its sanctity (Chliaoutakis et al, 2002). Although there are no studies concerned with the association of participation and religious beliefs, research has been done that associates the meaning of social capital and spirituality for nurses. Looman (2004) conducted a descriptive study in order to define social capital for nurses through the experiences of family caregivers of children with chronic conditions.

Looman (2004) argued that spirituality and its expression, by being part of a spiritual community, gave families a feeling of meaningfulness and the ability to endure difficult situations that could not be changed. She found that for families, God was a positive concept. Helping each other was an essential part of communities with a faith; problems were thought to lead to loss of faith or strengthening of faith. There was the belief that there is a divine plan for humanity and that things would turn out well at some point in the future.



This study did not reinforce the above findings. Participants stated that they were inspired by the Holy Bible to care for others and themselves as well. They did not mention the existence of a bond created in the community based on spirituality or that their faith was reinforced by their problems. They viewed their religion rather as a source of examples of how to live a good life and treat people in an ethical way. In addition, a spiritual community or a priest was not mentioned at all in their interviews. They referred to examples of the Holy Bible but they gave the impression that each one was referring to the examples that they felt personally closest to.

### **5.3.6 Participation, interpersonal relations and power**

Old persons' interactions with their environment influences their participation in nursing care. With their own words participants pointed out that relations among them and the system, nurses and doctors, family, neighbours and peers were the factors that determined their participation. Furthermore, relations that are developed among health care professionals can also influence the phenomenon of participation.

In the literature the association of interpersonal relations and participation in nursing care has not been researched. Even though Gerrish (1999) evaluated what nurses offer to community care in Great Britain, especially after the implementation of integrated nursing teams, there is no evidence of how these relations affect the public and how they might negotiate with services in the community. In Greece the high status of doctors and the relatively low status of nurses as well as the low numbers of nurses employed by the NHS does have an impact on the demonstration of the phenomenon of participation. This applies not only to the community but also to the NHS as a whole and was recognized by the participants.

According to Eurostat (2002) Greece has 438.4 doctors per 100000 inhabitants in comparison to U.K. that has 174.8 per 100000. In Greece, nursing duties are defined by each hospital separately (Giannopoulou, 1999) and if you compare them with the nursing training curriculum it is apparent that nursing duties are restricted to a

smaller field of practice in comparison to the expertise they acquire during their studies. In Greece doctors have very high social status and are highly respected. As evidence of the extent of this social phenomenon Dalla-Vorgia and Garanis (1991) mention the fact that there are almost no lawsuits against doctors in Greece.

Suhonen et al (2003) in their comparative study on patient autonomy in surgical care in five European countries (Finland, Spain, Greece, Germany and Scotland) viewed from the nurses' perspective, argued that the low educational level of registered nurses in Greece, together with their perceived low status of work, had a detrimental effect on nurses' ability to offer support to patients in order to help them participate in their nursing care. It is obvious that power relations among health care professionals can affect the delivery of a service and in this case participation. In the case of the Greek national health care system, there is a need to let service users express their opinions and say how they feel they are affected by the situation in the health care context.

The low status of nurses was also mentioned by the participants of this study. Power relations in the context of health care influences care giving and even the relationship that is developed with the recipients of health care. In this study, another problem that is acknowledged is the low numbers of nurses in hospitals (see p 202-203). This is sometimes reflected in nurses' presence being rare on the wards. There is the need to employ more nurses in order to meet health care needs. Uncontrolled and unsupervised lay participation in care cannot be an answer as it could compromise the quality of care. Although in this study, patients reported that they were forced to perform nursing duties because of the lack of nurses, it remains to be investigated whether this occurs often and what the implications for the provision of health care are. In addition, we need to hear the nurses' voice about the above debates to have a fuller picture.

Power and control are issues that have been studied extensively in the literature. In this study, the issue of power and control that exists within the health care context was highlighted in relation to participation. The interviewees expressed their

experiences of a disempowering environment that the health care system has developed for health care users. It is also evident that there seems to be a shift in the power balance in the community and the health care users are feeling more in control as they are in their own homes and they can also make the rules for health care professionals. On the other hand nurses do seem to be in control of their contact with patients as they are the experts that interact with a layman on specialist issues.

Performing this study made me reconsider my professionalism and I would suggest that this should be a significant impact of the study. Participants pointed out occasions that nurses ignored their needs and they were deeply affected, and I could see that I could be the one treating them like that and I would not have a clue. I would think that I was doing the best I could and that I had prioritised my work, but in reality my acts would have exactly the opposite result.

Other studies have reported that the provision of information is mostly the responsibility of nurses, who however often use the technique of closed questions to avoid being asked questions by patients. Furthermore, it was reported that patients were afraid that they would be punished by being offered less care if they asked too many questions. Patients also reported that nurses were not even interested in listening to them and as they were unwell they finally gave in and did as they were told by doctors and nurses (Henderson, 2002). This study reinforces these findings.

Suhonen et al (2003) performed a comparative study on patient autonomy in surgical care in five European countries (Finland, Spain, Greece, Germany and Scotland) from the nurses' point of view. The results showed that nurses felt that they did not provide enough support to patients in order for them to make decisions. The greatest difference was between Germany and Greece. It is not however clear if the authors' explanations derived from their research findings or if they attempted to provide an explanation based on their personal experiences and perceptions of the phenomenon. Although they provided a detailed description of the development of their questionnaire, the presentation of their results is vague and raises more questions than it answers.

In the literature the hospital setting was presented as a disempowering environment and highlighted the contrast that exists among hospitals and the community setting. Wellard et al (2003) reported that nurses intentionally maintained control over the provided care. The most experienced nurses considered participation as a process of keeping consumers fully informed in order to be able to make choices and decisions over their treatment, even their discharge; therefore, to be able to be in control. Whereas the nurses that had less work experience attempted to find excuses such as time limitations, the most experienced nursing staff expressed the opinion that nurses intentionally maintain control over the provided care through a variety of ways such as rules and regulations (Wellard et al, 2003). This practice minimizes autonomy and consequently participation.

Another researcher, Jones (1996), expressed the belief that a patient admitted to the ward will often lose their autonomy due to the 'ritualistic display of power' (Jones, 1996). She explained that this is demonstrated by the nurses wearing uniforms while the patients are wearing night clothes, as well as discussions that take place while nurses are standing and patients are lying or sitting down. The participants of this study reinforced these findings.

In the same vein, Muir-Cochrane (2000) studied issues of power and control associated with mental health nursing care provided in the Australian community context. She performed an ethnographic study, using participant observation. She discovered that nurses were perceived, by both themselves and patients, as powerful. The fact that they were healthy and had items or symbols of their status (name tags, diaries, etc) played a central role in their interactions with the patients. On the other hand, the context of the interaction, which was the patient's home and not a formal care-giving environment, influenced the power balance in the patient's favour. In the community the patient was the host and the nurse was the visitor. The patient was in their own environment which gave them more freedom of movement and decision-making regarding issues such as the length of the visit. Although nurses still had nursing interventions from which they could draw power, the patients maintained

control over the interactions. This study which was conducted in the community revealed the existence of a different power balance in comparison to the hospital setting.

### **5.3.7 Choice and participation**

In this study the overwhelming message was that old persons want and choose to participate. Furthermore, they want to be active members of their communities by participating actively in the nursing care of their families, friends and peers. Even though the interviewees strongly expressed their frustration with the weak points of the national health system, this did not seem to influence the positive outcomes of participation that they talked about.

There has been research carried out as to whether old persons do want to participate in nursing care but it was not sufficiently clear in the literature whether old persons wanted to participate in health care and if so to what extent. This study emphasises that old persons do want to exercise participation.

There is much discussion in the literature regarding the willingness of people to participate in nursing care and if they do, to what extent (see p. 30-33). In this study old persons expressed their willingness to participate but each one of them to a different extent and involving different tasks. Individual circumstances had shaped the form in which participation was exercised by each of them. All recognized their need to have a professional for issues that are critical and have them as a referral point. However, they did not want to have them dominate their lives or even their health care.

Rosén et al (2001) pointed out that patients will soon be in the position of having a wide range of choices because some solutions might not be acceptable by patients and also because the number of treatment alternatives is growing. Therefore, whether or not patient participation is beneficial for the patient, it will become increasingly



important in health care practice. Nevertheless, this study suggested that participation is a necessity for the interviewees and meets needs that are not being met adequately or even at all by the national health care system.

Litva et al (2002) performed a study to investigate the degree to which the public was willing to be involved in decision-making in health care in Great Britain. Respondents tended to be more willing to participate at a health care system level and in programs that were operated by health care professionals. On the other hand, they were not willing to take part in decision-making at a patient level. It was evident that they wanted to be consulted but not held responsible for the decisions that had to be taken. The study participants thought that they could provide useful insights that would improve the health care system and the programs provided. In case their feedback was not taken into consideration by health care authorities, they wanted proof they have been heard and the rationale behind the decision explained to them.

In this study, participants' strong criticisms of the system can be considered as willingness to participate in the critical evaluation of services, an essential element of participation. In fact, the interviewees can be said to be participating already, by taking the situation into their hands and doing their best to improve their everyday lives. They are not passive recipients of nursing care but have a strong sense of what their rights should be and how they would like their situation to be. When the situations do not meet their expectations, they attempt to improve them. What was however absent from their stories was an organized structure within the national health care system that would listen to their voices and take action based on their criticisms and suggestions.

Kirk and Glendinning (1998) claimed that formal and informal nursing care is set to change dramatically due to the shift of hospital care to community (home) focused care. Health and Social Care directives in Great Britain have a pivotal role in this change. These are however based on WHO directives that have a worldwide influence. Therefore, their claims may well be true for any other country that has adopted the same WHO directives.

There is literature (Tutton, 2004) that suggests that nurses struggle to achieve participation when caring for patients with verbal communication problems within an unhelpful environment, insufficient time and team co-operation difficulties. On the other hand, Tutton's findings showed that the patients were concentrated on dealing with their ill-health, fit in whenever and wherever possible and expressed their gratitude for the care they received.

### **5.3.8 The burden of participation**

Participants in this study expressed a preference to stay in their own homes and be cared for by their own relatives or friends. Family members want to take care of each other but they also feel the burden, both emotional and financial, that this bestows on them if they are solely responsible for it. It would be safe to assume that the public needs to assist people to stay in their homes safely. Nursing services thus need to offer support to those that undertake the role of the carer and give them the ability to have time and space for themselves. They should not need to sacrifice themselves for the care of their family.

Again this requires flexible nursing care that will work with the persons involved and meet their needs as required. Carers also need to be listened to and have their needs met as this is the only way in which they can continue offering their help. In a society with a growing old population, health care services need to evaluate increasing demands and feasible ways of meeting these. It has been shown in the past that communities and individuals have taken initiatives and met needs, for example, younger people caring for the older members of their families and communities. In the future, health care services will have different expectations and the consistency of the population will change. Individuals need to be able to care for themselves and then be able to offer their help when they are willing to do so without having this activity compromise their own well-being.

People need to participate in their nursing care and are clearly willing to do so. However, this should not lead to services that neglect the negative developments of this phenomenon. Participating adults mean nurses have a greater responsibility to maintain a high level of the care that is provided.

Strong criticism of an indifferent national health system was expressed in this study, particularly by people who need nursing care at home and are experiencing the emotional and financial burden of caring for others while themselves experiencing a variety of problems. Participation should be carefully controlled and not left to fill in the gaps of a national health system that is not able to meet the health care needs of the public. In the future this needs to be taken in consideration.

Moreover, participants of this study expressed the view that they did not expect their views to be heard and they did not expect anything from the organized services. Not only were their needs not being met, they were also so discouraged that they could lack the motivation to express their needs or complain to the services. People should be consulted when designing services and their needs should guide implementation as discussed earlier. Furthermore, old persons need to have their voices heard as service users and also hold responsibility for the consequences of their self-determination for health and well-being.

It is widely recognized that patient participation is a necessity but that does not excuse the compromise of the provision of nursing care to those who need it. If nurses cannot make sure that the number of nurses is increased to meet health care needs satisfactorily, they need to develop practices that will educate, control and train the public when necessary up to an acceptable level that will cause no harm to those involved.

Participation can be an experience that can have negative consequences on people's lives, especially in the case of a person who has adopted the role of a carer for a loved one. Brearley (1990, p5) in her literature review regarding patient participation

mentioned that concerns were also expressed about potential risks of user participation:

‘possible increased delay in seeking care, ill effects of self-diagnosis and self-medication, risks of conflicting advice, danger of uncontrolled and unevaluated treatment, misuse of highly technical information, alienation of professionals’.

Hoskins and Carter (2000) addressed the issue of socio-economic inequality and proposed a new role for community nurses working in the United Kingdom. They claimed that nurses could improve community health by identifying and improving those life circumstances that create financial difficulties which in turn have an effect on the person’s well being. This is something that it is not implemented in the Greek NHS. Furthermore, participation can take the form of financial participation in the cost of care and become a distressing burden.

Greek patients have to deal with the financial burden that a mismanaged national health system bestows on them. Liaropoulos and Tragakes (1998) pointed out that there are a variety of expenses that a patient deals with although the national health care system is based on the ideal of offering free health care to all citizens. This could be in the form of contributing to the payment of medication, in the use of private health care and diagnostic services and bribes to doctors working for the NHS in order to be seen more quickly or obtain more attention by the treating physician.

Brearley (1990, p5) in her literature review regarding patient participation mentioned that concerns were also expressed about potential risks of user participation:

‘possible increased delay in seeking care, ill effects of self-diagnosis and self-medication, risks of conflicting advice, danger of uncontrolled and unevaluated treatment, misuse of highly technical information, alienation of professionals’.

In my study the participants showed high levels of awareness of the above risks and this resulted in making them feel anxious. In their cases anxiety was compounded by

the organizational deficiencies of the NHS, which was not pointed out in other papers.

It appears to be in this study that participation in nursing care can be demanding, therefore tiring, particularly for frail old persons and those with general health problems. Fatigue can be both emotional and physical. This is an element of participation that has not been thoroughly investigated in the literature. The main consequence could be neglecting to perform tasks that are essential for the maintenance of health and prevention of disease.

There are studies that have indicated that self-neglect can be a serious drawback for participation. Lauder (2001) attempted to illuminate the concept of self-neglect in relation to self-care. His literature search revealed that self-neglect can be a conscious choice of the person or it can be a result of a limitation of self-care ability due to disease. In the context of the increasing importance of participation in health care, this poses ethical dilemmas to health care professionals. Nurses aiming to involve persons in care have to bear in mind that limitation in abilities due to ill-health can lead to persons receiving inadequate nursing care. To this we can add the data of this study which imply that fatigue can be another reason for self-neglect.

What is not reported here is the occurrence of self-neglect as a consequence of participation. Lauder (2001) in his literature search revealed that self-neglect can be a conscious choice of the person or it can be a result of a limitation of self-care ability due to disease. In this study participants expressed the fear of not being able to do things in the best way possible which could have resulted in lowering their standards of care. This study suggests that the Greek national health care system has considerable organizational deficiencies that oblige patients to be actively involved in their health care in order to be able to meet their needs.

### **5.3.9 Information giving**



In this study it became clear that participants needed more information from health care professionals and to be given the option of the level of their participation. Service users tend to obtain information from a wide variety of sources which can have both positive and negative consequences. Findings reinforce this argument as participants were encouraged or discouraged by the nurses' attitudes to participate. It became evident in the interviews that information giving was essential for participation. When information giving was not adequate, participants were not able to participate. Information giving and the attitude of professionals towards this were stated to be disappointing. Patients explicitly reported that they only felt comfortable making a decision and participating in care when they were given adequate information.

The need for nurses to give more information and their ability to do so should be developed throughout nursing training and enhanced further with seminars during their professional practise. The provision of information and training to lay people is a complex activity that needs to meet individual needs and is based on good communication. In this study participants complained of not being able to obtain enough information; making enquiries was mostly an unpleasant and unsatisfactory activity. As information is the basis of participation, nurses need to gain new skills. They need to listen more and they need to be able to inform and train lay people to perform nursing tasks without compromising the quality of their care. It remains to be decided how nurses can become more effective in information giving and enhancement of patient participation. More research is needed to investigate and tackle the reasons for this phenomenon of inadequate information giving, and at the same time develop new skills to achieve better communication with patients.

Allen (2000) indicated that information and choice about treatment was one traditional way through which health care professionals maintained control over patients. She herself had evidence that although nursing staff were willing to provide information regarding medication, they could demonstrate a defensive attitude as they considered such questions as questioning their way of thinking and their treatment decisions. This occurred in the ward where patient participation was

confined to task allocation. On the contrary in this study I would argue that patients were under pressure to undertake a more active role in their care as there was a shortage of nursing staff.

It is suggested that Greek nurses feel that they do not provide enough support to patients in order for them to make decisions (Suhonen et al 2003). The researchers in this case attributed this to cultural differences or the potential differences in the nursing roles among the participating countries (Suhonen et al 2003). As far as maintaining autonomy for their patients, Greek nurses appeared to be less successful in comparison to the other countries. The main reasons identified were related to the low educational level of registered nurses and their perceived low work status. This is an issue that would be very interesting to be studied in more depth.

Patients reported (Henderson, 2002) that they felt comfortable to make a decision and participate in care only when they were given adequate information. Provision of information was reported to be mostly the responsibility of nurses, who would however use the technique of closed questions to avoid being asked questions by patients. In addition it was reported that patients were afraid that they would be punished by being offered less care if they asked too many questions. Patients reported that nurses were not even interested in listening to them and as they were unwell they finally gave in and did as they were told by doctors and nurses.

In the literature it is suggested that old patients are not given adequate information or the respect they ought to be given. Philp (2001), in his literature review on maintaining the dignity and autonomy of older persons in the health care context, claimed that the literature suggests that the dignity and autonomy of older patients are undermined in health care settings. This results in insensitivity towards their needs and desires, lack of information-giving and therefore, lack of opportunity to make informed choices. He reported that these are the findings of surveys conducted mainly by older persons' advocacy groups. This literature review pointed out the significance of researching old persons' views, especially about the phenomenon of participation in which they are expected to have an active role.

My study suggests that patients were not given information or any opportunity to make informed choices. This study demonstrated that interviewees felt frustrated as they reported a lack of support to participate and make choices regarding their health care.

Jewell (1994) revealed that nurses consider some patients, such as older patients, and those cognitively impaired or with insufficient communication skills, incapable of participating in nursing care. Nurses pointed out that, in such cases, relatives and carers are approached in order to be involved in the patient's care. Although in my study this was not explicitly reported, there were complaints in the second set of interviews that old persons had been dismissed and their relatives were informed in more detail than they had been.

Furthermore, there is literature that connects ageism (which has been defined as a widespread perception of old age in society, which is characterized by biased, unfair and one-sided perceptions about a group of members of society based only on age) with the described phenomena. Lookinland and Anson (1995) reviewed the literature in order to identify ageist attitudes demonstrated by health care staff. They performed a survey to determine factors that contributed to ageist perceptions and the implications these have for elderly care. Literature presented old age as the gradual loss of abilities and energy accompanied by disease (Lookinland and Anson, 1995).

Although there was a widespread feeling of frustration among participants, not all of them expressed the view that their old age was the factor that determined the attitudes of health care professionals towards them. A large part of them thought that this was a reality in health care that all patients dealt with, regardless of their age.

### **5.3.10      The positive view of participation**

As far as the positive outcomes of participation are concerned, this study reinforces the findings of previous studies. As already discussed there are also negative outcomes.

It is obvious from the present study that participation is a rewarding experience and old persons are motivated to participate because of that, but nurses should always take into consideration the negative outcomes of participation so that their practice will enhance the positive outcomes and minimize the negative ones.

Reward as an outcome of participation is congruent with the literature. This aspect of old persons' participation was revealed for example in a report about a project in a rural Scottish area. Age Concern Scotland developed a project in Fife (Barnes & Bennett, 1998) in order to enable older people who could not leave their homes without assistance to meet in order to express their needs and experiences. They went on to evaluate the project. The participants perceived the project as a positive experience that benefited them in multiple ways. This was an experience that enhanced their social lives, boosted their self-esteem and helped them learn from one another but the study did not report any increased capacity to control their lives.

This study has also associated participation with personal development. There is evidence in the literature that associates participation with personal development. Mok (2001) in his evaluation of self-help groups reported positive outcomes. The researcher used a purposive sample and 449 valid questionnaires were filled in. The vast majority of respondents reported that they enjoyed positive outcomes including the 'Outlook on life (more positive, hopeful, open, gregarious, confident, decisive in taking action); Personal ability (learned how: to accept others; help, maximise their strengths, appreciate others' merits etc); Emotional control (learned to care for others, be considerate); Relationship and knowledge about society' (Mok, 2001; p 121).

It is suggested in the present study that participation in nursing care is an on-going process that enhances both care-related skills and the participants' personalities as a

whole. Thus, participation in nursing care needs to be viewed as a complex activity that influences the whole person. It does not only affect somebody's health but also their personality and its qualities.

Participants not only related participation in nursing care to their personal development but also stated their awareness of the fact that this relation exists and that they were keen to take advantage of this fact. Participation thus is being moved forward by a new wave of people who are not only active patients (Brearley, 1990) but are aware of this status and use this characteristic for their personal development.

Moreover, a new element that came out of this study is that participation in nursing care can be viewed by participants as an achievement under certain circumstances. The experience that was reported in this study concerned learning how to use modern technology, the internet, to retrieve information regarding health care. On the other hand the literature pointed out ageist attitudes (see p. 53-55) that do not consider old persons able to participate. For example, Jewell (1994) revealed that nurses consider some patients, such as older patients, patients cognitively impaired or with insufficient communication skills, incapable of participating in nursing care.

It is well documented in the literature that participation in nursing care is associated with higher levels of satisfaction for participants. Thus, participants reporting that satisfaction is gained from participation is nothing new but a verification of what is already known. For example, Cahill (1996) in her concept analysis of patient participation, summarized the consequences of patient participation, as reported in the literature, as follows:

'a sense of contribution by the patient, improved nurse-patient communication and satisfaction, better patient adjustment, decreased number of complaints, feedback about services provided, patient empowerment, enhanced decision making, enriched quality of life, increased understanding and better management of care at home, diminished feeling of powerlessness, apathy and dependency, loss of clinical independence on part of nurse, emotional stress for both nurse and patient,' (p 568).



Cahill saw satisfaction as one of the positive consequences of participation.

In addition, Piercy et al (1999) conducted a research project in order to find out older patients' views about the shared decision-making program they developed (concerning patients with benign prostatic hyperplasia). They surveyed 678 participants before and after the programme. The majority of the participants were interested in obtaining information about their condition and participating actively in the decision-making process. The study showed that participation enhanced their relationship with their physician and their satisfaction. Xu (2004) also indicated that patient satisfaction is enhanced by patient participation. Although this study, like the previous one, was performed by medics, it still gave interesting results concerning the issue under investigation.

It is worth mentioning that satisfaction is one of the characteristics of participation that is both a result of and a motive for participation. It can however be used by health care professionals to enhance their relationship with patients as well as initiate and maintain their participation. It is significant that participants of this study expressed the feeling that participating in nursing care can be a source of personal satisfaction. They felt satisfied with themselves because they could still succeed and remain active and able to take care of themselves and offer help to others.

This study suggests that old persons are able to participate and furthermore, they are able and willing to learn new skills and take initiative. Participation can even be a rewarding experience that can contribute to further development of patient participation in the healthcare context. Therefore, it is vital to offer opportunities to old persons.

Furthermore, participants of this study revealed that participation in nursing care made people feel security. The issue of security has been tackled in the literature, but only in relation to social capital. It is argued in the literature (Cowley and Hean, 2002) that it is beneficial for people to live in communities where neighbours are familiar with their neighbours and they trust each other and a cycle of support is existent (people help others knowing that they are also going to get help in return at

some other point). The issue of people feeling safe interrelated with the issue of trust in the participants' stories.

## **5.4 Summary**

Participation is a multidimensional phenomenon in the health care setting. In view of modern developments, including technological and scientific developments, as well as the unprecedented growth of the old population, elucidating its nature is a necessity. Societies need to see what the current views and challenges are and develop health care services that will meet the needs of the public. People's views and experiences should be explored so that health care professionals can gain insights into the perceptions of service users and be able to evaluate their practice as well as design and implement new services alongside the improving old ones.

In this study the phenomenological approach has explored the participants' views and experiences and gained an understanding of the meaning of participation in nursing care for old persons. The knowledge that was gained can improve nursing practice, influence policy planning in the health care sector within person-centred philosophy and initiate more research in this field. Because phenomenology focuses on clients' experiences and enables their needs to be identified, it can be used to plan future care. Therefore, the results of phenomenological research can contribute to the provision and justification of high quality care. However, although this study offers a glimpse into participation and what it can mean, more phenomenological studies need to be performed not least in exploring the experiences of nurses.

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## **list of participants**

Mrs A

Mrs B

Mr C

Mrs D

Mr E

Mr F

Mr G

Mr H

Mrs I

Mr J

Mrs K (not available for the second interview)

Mrs L

Mrs M

Mrs N

Mrs O

Mrs P

Mr Q

Mr R

Mr S

Mr T

Mr U (refused the second interview)

Mr V

Mrs W

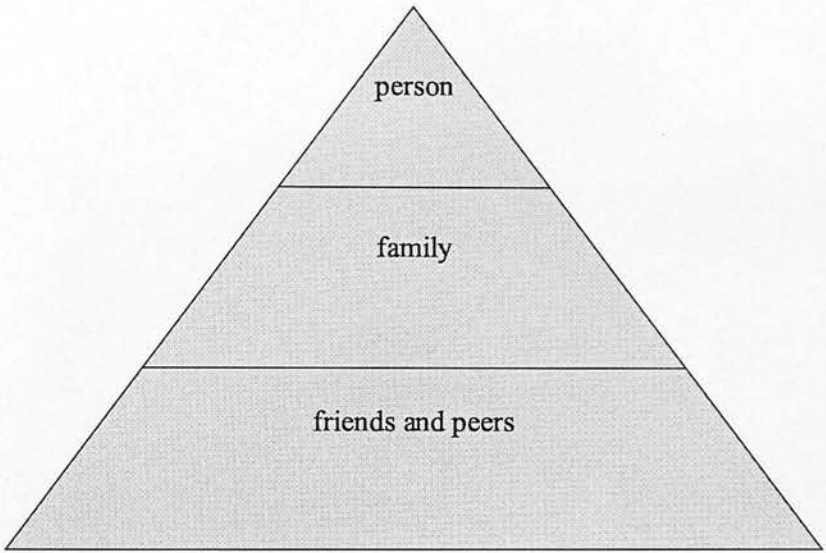


Figure 1: Participating parties: own self, family, friends, neighbours and peers.

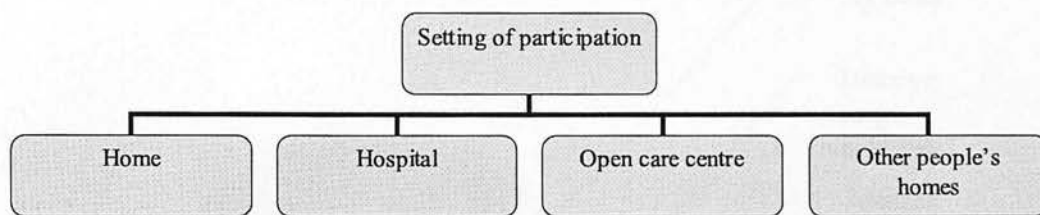


Figure 2: Setting: own home, hospital, open care centre, other people's houses.

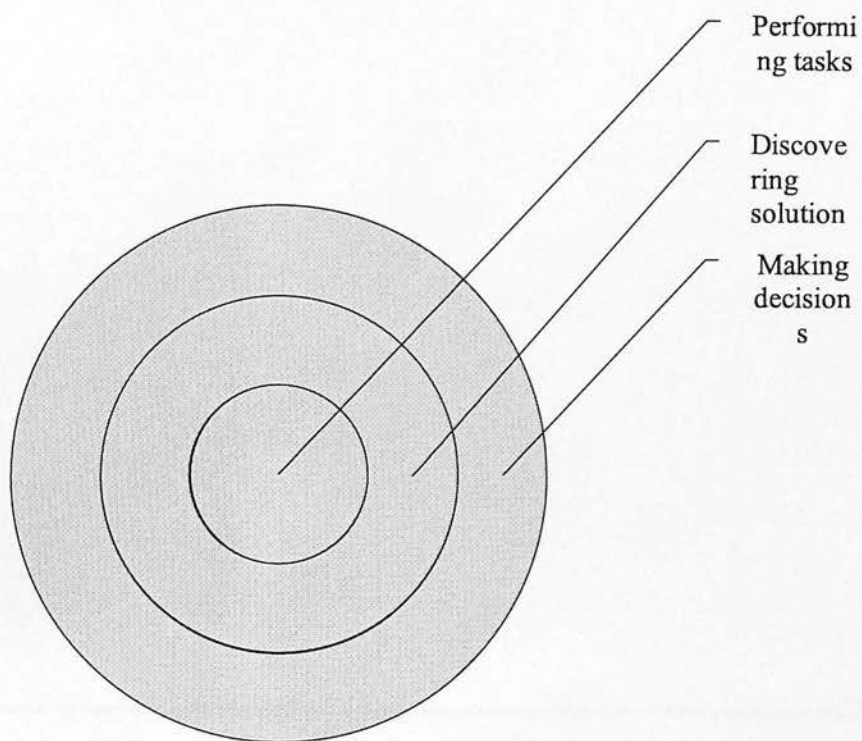


Figure 3: Level of participation: performing tasks, making decisions, discovering solutions.

## APPENDIX A



ΑΙΚΑΤΕΡΙΝΗ ΚΑΣΙΔΗ

ΠΑΝΕΠΙΣΤΗΜΙΟ ΤΟΥ ΕΔΙΜΒΟΥΡΓΟΥ

ΠΡΟΣΚΛΗΣΗ ΓΙΑ ΣΥΜΜΕΤΟΧΗ ΣΕ ΕΡΕΥΝΑ

ΘΕΜΑ

Το νόημα της συμμετοχής των ηλικιωμένων στη  
νοσηλευτική φροντίδα

Ενημέρωση για τους πιθανούς συμμετέχοντες

Η έρευνα θα επικεντρωθεί στις απόψεις και εμπειρίες των ατόμων ηλικίας άνω των 65 ετών που ζουν στο σπίτι τους και είναι κοινωνικά ενεργοί. Οι συμμετέχοντες θα ζητηθεί να μοιραστούν με την ερευνήτρια τις απόψεις και εμπειρίες τους όσον αφορά τη συμμετοχή η και την έλλειψη συμμετοχής στη νοσηλευτική φροντίδα των ιδίων η μελών της οικογένειάς τους.

Οι συμμετέχοντες θα δώσουν συνέντευξη διάρκειας μιας ώρας στον ειδικά διαμορφωμένο χώρο του Κ.Α.Π.Η. Οι συνεντεύξεις θα μαγνητοφωνηθούν. Το περιεχόμενο των συνεντεύξεων είναι εμπιστευτικό και δεν θα έχει πρόσβαση άλλος από την ερευνήτρια. Το όνομα των συμμετεχόντων και οι υπόλοιπες πληροφορίες που αφορούν την ταυτότητα των συμμετεχόντων είναι

στοιχεία επίσης εμπιστευτικά. Ένα μέτρο για τη διασφάλιση της ανωνυμίας των συμμετεχόντων θα είναι η χρήση κωδίκων και όχι ονομάτων για τις κασέτες.

Τα οφέλη που θα απορρέουν από τη συμμετοχή στην ερευνά δεν είναι άλλα από τη συμβολή στη βελτίωση της παρεχόμενης νοσηλευτικής φροντίδας αλλά και των υπηρεσιών υγείας γενικότερα.

Τέλος η συμμετοχή δεν είναι υποχρεωτική και εφόσον κάποιος αποφασίσει να συμμετάσχει μπορεί να αποχωρίσει από την έρευνα οποιαδήποτε στιγμή το αποφασίσει. Πριν αποφασίσει αν θα συμμετάσχει μπορεί να ζητήσει να ενημερωθεί ατομικά από τον ερευνητή και να λύσει οποιαδήποτε απορία του έχει δημιουργηθεί σχετικά με την έρευνα.

Η ερευνήτρια θα βρίσκεται στο χώρο του Κ.Α.Π.Η. στις 18, 19 και 20 Ιουνίου για την προσωπική ενημέρωση των συμμετεχόντων και την πραγματοποίηση συνεντεύξεων.

## **APPENDIX B**

**APPENDIX B**  
**INFORMED CONSENT FORM**

**PROJECT TITLE:**

**RESEARCHER:**

This is to certify that I,  
agree to participate voluntarily in this research project.

I am aware that any treatment I might receive is not going to be affected as a result of participating in this research project. I am aware of my right to withdraw at any time and refuse to answer specific questions during my interview.

I give permission to be interviewed and my interviews to be tape-recorded.

I have been given the opportunity to ask questions and I was given all the necessary explanations.

## APPENDIX C



ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ  
ΠΕΡΙΦΕΡΕΙΑ [REDACTED]  
ΔΗΜΟΣ [REDACTED]  
[REDACTED] ΚΑΠΗ

[REDACTED]  
Αριθ. Πρωτ. ...✓...

**Β Ε Β Α Ι Ω Σ Η**

Το [REDACTED] ΚΑΠΗ - [REDACTED] ενημερώθηκε και ενέκρινε την πραγματοποίηση συνεντεύξεων μελών του από την Κα Αικατερίνη Κασίδη ( R.G.N. , M.S.C. ).  
Εγκρίθηκε η πραγματοποίηση συνεντεύξεων στα πλαίσια της διδακτορικής της έρευνας για τη χρονική περίοδο που εκτείνεται έως τα μέσα Ιανουαρίου 2004.

[REDACTED] ΚΑΠΗ  
[REDACTED]  
[REDACTED]



ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ  
ΠΕΡΙΦΕΡΕΙΑ [REDACTED]  
ΝΟΜΟΣ [REDACTED]  
[REDACTED] ΚΑΠΗ  
ΔΗΜΟΥ [REDACTED]

Αρ.πρωτ :Δ.Υ.

Πληροφορίες:Κα [REDACTED]

ΤΗΛ & FAX [REDACTED]

ΠΡΟΣ:

Αξιότιμοι κύριοι,  
Θα θέλαμε να σας ενημερώσουμε, ότι η φοιτήτρια Κασίδη Αικατερίνη, μας  
πληροφόρησε σχετικά με την έρευνα <<συμμετοχή στη Νοσηλευτική  
φροντίδα>> και πήρε την άδεια για να πάρει συνεντεύξεις από τα μέλη μας

Με εκτίμηση

[REDACTED]  
ΤΟΥ [REDACTED] ΚΑΠΗ ΔΗΜΟΥ [REDACTED]  
[REDACTED]  
[REDACTED]

ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ  
ΝΟΜΑΡΧΙΑ [REDACTED]  
ΔΙΑΜΕΡΙΣΜΑ [REDACTED]  
ΚΕΝΤΡΟ ΑΝΟΙΚΤΗΣ ΠΡΟΣΤΑΣΙΑΣ  
ΗΛΙΚΙΩΜΕΝΩΝ Κ.Α.Π.Η.  
ΔΗΜΟΥ [REDACTED]

## ΒΕΒΑΙΩΣΗ

Το Κ.Α.Π.Η. [REDACTED] ενημερώθηκε και ενέκρινε την πραγματοποίηση συνεντεύξεων των μελών του από την κα. Αικατερίνη Κασίδη (R.G.N., M.S.C.)

Εγκρίθηκε η πραγματοποίηση συνεντεύξεων στα πλαίσια της διδακτορικής της έρευνας για τη χρονική περίοδο που εκτείνεται έως τα τέλος Μαρτίου.



Προς την  
κα. ΚΑΣΙΔΗ ΑΙΚΑΤΕΡΙΝΗ

**ΒΕΒΑΙΩΣΗ**

Βεβαιώνουμε ότι η κα. ΚΑΣΙΔΗ ΑΙΚΑΤΕΡΙΝΗ θα πραγματοποιήσει έρευνα στο χώρο του ΚΑΠΗ Δήμου με θέμα: **“ Το νόημα της συμμετοχής των ηλικιωμένων στη νοσηλευτική φροντίδα ”**

Το χρονοδιάγραμμα της έρευνας έχει ως εξής:

1. 10-20/6/2003 : πραγματοποίηση της πιλοτικής έρευνας (2-4 συνεντεύξεις)
2. 10-20/8/2003 : πραγματοποίηση συνεντεύξεων
3. 10-30/9/2003 : πραγματοποίηση συνέντευξης (συνέχεια)

Τη βεβαίωση αυτή ζήτησε η ενδιαφερόμενη για να τη χρησιμοποιήσει στο Πανεπιστήμιο του Εδιμβούργου

η οποία εμπεριέχει από το

ΚΑΠΗ

ΔΗΜΟΥ

HELLENIC REPUBLIC  
PREFECTURE OF [REDACTED]  
DISTRICT [REDACTED]  
CENTER OF OPEN PROTECTION  
FOR THE AGED C.O.P.A. (K.A.P.H.)  
MUNICIPALITY [REDACTED]

## C E R T I F I C A T E

THE C.O.P.A. [REDACTED], WAS INFORMED AND HAS APPROVED  
THE REALIZATION OF INTERVIEWS TO THEIR MEMBERS, BY  
Ms EKATERINI KASIDI (R.G.N., M.S.C.).

THE REALIZATION OF INTERVIEWS WAS APPROVED IN THE FRAME  
OF Ms KASIDI'S DOCTORAL (Ph.D.) RESEARCH, FOR THE TIME  
PERIOD EXTENDED UP TO THE END OF MARCH.

[REDACTED]  
[REDACTED]  
SEALED AND SIGNED  
[REDACTED]

Official translation of the attached document

Athens, 27.3.2004/The translator, Athena Daviou *A. Daviou*



No.:  
No: 05861

HELLENIC REPUBLIC  
PREFECTURAL SELF GOVERNMENT OF [REDACTED]  
Municipality of [REDACTED]  
[REDACTED] Center of Aged People Occupation

[REDACTED]  
Ref. No: 208

To: Mrs. KASIDI Ekaterini

CERTIFICATE

We certify that Mrs. KASIDI Ekaterini will materialize a research, approved by the [REDACTED] Center of Aged People Occupation, at its location at the Municipality of [REDACTED] with subject-matter: **"The meaning of the aged people participation in nursing care"**.

The timetable of the research has as follows:

1. 10-20/6/2003: Pilot Research (2-4 interviews)
2. 10-20/8/2003: Interviews
3. 10-30/9/2003: Continuance of Interviews

This certificate was issued after the request of the interested in order to use it at the University of Edinburgh.

[REDACTED] Center of Aged People Occupation  
(Signature)  
[REDACTED]  
[REDACTED] of the Municipality [REDACTED]  
Official Stamp of the [REDACTED] Center of Aged People Occupation

Athens, January the 21<sup>st</sup> 2004.

Official translation of the attached Greek original document.

The translator

M. L. DRAKOPOULOU

No.:  
No: 05861

HELLENIC REPUBLIC  
PREFECTURE OF [REDACTED]  
MUNICIPALITY OF [REDACTED]  
[REDACTED] Center of Aged People Occupation

[REDACTED]  
Ref. No: —

CERTIFICATE

The [REDACTED] Center of Aged People Occupation [REDACTED] after being informed, approved the interviewing of its members by Mrs. Ekaterini KASIDI (R.G.N., M.S.C.). The materialization of the interviews was approved in the framework of the doctoral research extended for the period till the middle of January 2004.

[REDACTED] Center of Aged People Occupation  
(Signature)  
[REDACTED]  
Official Stamp of the 1<sup>st</sup> Center of Aged People Occupation

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Athens, January the 21<sup>st</sup> 2004.  
Official translation of the attached Greek original document.  
The translator  
M. L. DRAKOPOULOU

No.:  
No: 05861

HELLENIC REPUBLIC  
PREFECTURE OF [REDACTED]  
[REDACTED]  
[REDACTED]

Center of Aged People Occupation  
Municipality of [REDACTED]  
Information: Mrs. [REDACTED]  
Telephone & Fax: [REDACTED]  
[REDACTED]

Dear Sirs,

We would like to inform you that the student KASIDI Ekaterini, informed us in point of her research "participation in Nursing care" and was authorized to interview our members.

Sincerely Yours

[REDACTED] Center of Aged People Occupation of [REDACTED]  
(Signature)

Official Stamp of the [REDACTED] Center of Aged People Occupation

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Athens, January the 21<sup>st</sup> 2004.

Official translation of the attached Greek original document.

The translator  
M. L. DRAKOPOULOU